

Shifting Gears

Consumers transforming health

A WHITE PAPER

Shifting Gears — Consumers Transforming Health

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Acknowledgements

We acknowledge the lands of the First Peoples upon which this white paper was written and pay our respects to Elders past, present and future.

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The Consumers Health Forum of Australia is the national peak body representing the interests of Australian healthcare consumers and those with an interest in health consumer affairs, with a network reaching millions of Australian consumers.

CHF has the capacity, credibility and authenticity to ensure that governments and decision makers hear and understand the consumer perspective. Our members are diverse: they cover organisations and individuals with key conditions and issues across the health system and include professional, research and other health sector bodies.

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“Without informed, knowledgeable and articulate health consumers, health policy will always be unbalanced whatever the goodwill and idealism of governments and health providers. Mature consumer organisations are an essential part of the health equation”

The Hon Neal Blewett, Minister for Community Services and Health, speech to CHF’s Selecting Our Priorities Conference for Consumer and Community Groups, 1988

“All Australian Governments should re-configure the health system around the principles of patient-centred care, with this implemented within a five-year timeframe”

Productivity Commission, Shifting the Dial: 5 Year Productivity Review, 2017

“Health systems need to maximise the efficiency of health services and long-term care...they also need, fundamentally to deliver improvements that matter to patients and their changing care needs...people-centred care should better guide the course taken by health care in the future”

Ministerial Statement, OECD Health Ministerial meeting, January 2017

“Value will be rewarded over volume, consumers will be empowered and viewed as a valuable health resource, humanity and relationships will be essential elements of care, and technology will be used to decrease costs and increase access to care”

Future of Health: Shifting Australia’s focus from illness treatment to health and wellbeing management, CSIRO Futures, 2018

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FOREWORD

Over thirty years of consumer advocacy in health at the national level is reason to ponder the direction of health care and the role consumers and communities will play in shaping our health care future.

It is common belief that we need more preventative and integrated primary health care. The hospital of the future will look very different from the hospital of today. Changes to how health care is delivered are going to accelerate at an unprecedented pace driven by digitalisation, consumer expectation and the advent of genomics and precision, personalised medicine.

Consumers will assume a 'new power'. They will command convenience and access to high value, modern, personalised services that meet their needs. They will expect to have choice and control over the services they pay for. They will be activated more than ever with access to burgeoning information and innovations that will assist them to stay well, self-manage and access quality care tailored to them.

Policy makers, health administrators and clinicians – where decision making power currently rests - will need to learn new ways to harness the transformative role consumers can play as agents of change and to work with this 'new power'.

Consumer advocacy has already contributed in many ways to shaping our system, but there is still a way to go for this role to be truly valued and to achieve a truly consumer-centred health care system in Australia.

There is more to do to fully realise the many and varied roles that consumers can play in health care. The sooner we do that, the better health system and better experiences consumers will have.

This White Paper is the Consumers Health Forum of Australia's philosophy and aspirations for the future role of consumers shaping health. Over twenty consumers, researchers, clinicians and leaders at the forefront of health policy in Australia, observers from outside the direct health care sector as well as leading global thinking have contributed to the Paper.

Commentators describe the need for fundamental shifts in the way we conceive, finance and organise health care. They point to the value of consumer insights and experiences as the hidden assets in shaping a better system. It is therefore apt that we title this White Paper *Shifting Gears: Consumers Transforming Health*.

We highlight the journey so far and review the gains made over the last three decades as the role of the health consumer advocate and health consumer organisation has emerged and matured.

We examine the shifts that need to occur to ensure our health system is fit-for-purpose and best meets community needs and expectations.

We prescribe our ambition for the current and future roles we see consumers taking in system innovation and improvement to realise that future and make recommendations about how we should further support and strengthen these roles.

There can be no more important an investment than to equip the beneficiaries of our health system with the skills to shape it. We trust you enjoy reading our prescription for how.



Tony Lawson
Chair



Leanne Wells
Chief Executive Officer

THE JOURNEY SO FAR

For several decades there has been recognition of the need for a more active role for consumers in health care, what is often referred to as consumer ‘choices’ and consumer ‘voices’ aiming to improve service delivery, consumer experience and health outcomes. The impetus for consumer involvement in health care has continued to grow and change over the decades. Although several consumer organisations have been active since the 1950s, momentum built in the 1960s and 1970s with the emergence of the patient’s rights movement as part of a larger scale citizens’ and human rights movement. In more recent years, three additional factors have led to more active engagement of consumers. These include the changing nature of patient profiles the rising number of individuals living with complex and chronic conditions, large scale reforms to the health systems which have swept most developed countries and the involvement of the consumer movement in the consumer safety agenda, that is, monitoring and developing strategies for responding to medical errors and adverse events.

The Consumers Health Forum of Australia

Since establishing in 1987, the Consumers Health Forum of Australia (CHF) has been a voice for consumers in national health policy discussions. CHF arose from a group of community organisations who were frustrated with the absence of involvement of consumers and the community in government decision making and lack of action in key areas of community health and safety. Organisations such as the Australian Consumers Association and the Australian Federation of Consumers’ Organisations and state-based groups were dealing with health consumer issues in a piecemeal way. In May 1985, seven other organisations including ACOSS, the Public Interest Advocacy Centre, Combined Pensioners Association and the Doctors Reform Society joined to present the then Health Minister, Neal Blewett, with a Petition for Reform. Phillipa Smith of the Australian Consumer Association (ACA) led negotiations in which the group strongly criticised the Department of Health for its “secretiveness, lack of consultation with community groups and lack of action in areas including community health and safety”

Doctors, industry groups and bureaucrats had a virtual monopoly on decision-making which affected the health and health care of consumers. Dr Blewett granted \$13,000 for a consultant for a review into community participation in the department. The groups provided four representatives to the review which also included departmental officers. Louise Sylvan, CHF’s inaugural

Executive Director, wrote at the time that Dr Blewett was sympathetic to community participation in health but that there were also other reasons for him to be supportive: the recently-concluded NSW doctors’ dispute, continually rising health expenditures and increasing demands of new technology in health care.

The resulting Review of Community Participation in the Commonwealth Department of Health presented to the Minister in December 1985 found virtually no participatory avenues for consumers in the department and identified the need for a strong cohesive community lobby to provide the department with guidance to balance the representations of well organised professional and industry groups.

The Review’s first recommendation was for a coalition of consumer and community groups “totally independent” of the department to provide a strong community voice on health issues. Briefings of consumer and community groups began, governance questions were discussed and in the 1986 Federal Budget, the Minister announced that a “health forum” made up of representatives of community groups would be established with a budget of \$200,000. The originally named “Health Consumers Forum” was quickly renamed the Consumers Health Forum after it was realised that the HCF acronym was that of a health fund. The minutes of the first meeting of the CHF’s general committee give its aims and objectives as to:

- Provide a vehicle for consumer protection
- Promote preventative approaches to public health

- Recognise and help meet the special needs of disadvantaged groups
- Encourage consumer participation in health policy and decision making
- Ensure health consumers know their rights and that these rights are upheld¹.

Over the subsequent thirty plus years, CHF has represented and supported Australian health care consumers through policy responses to government; partnerships on research and other projects with the research community and other non-government organisations; and an ever-expanding network of consumer advocates that participate on national committees, policy forums and roundtables. Value to CHF's members include the opportunity to contribute to flagship policy activities such as Election Platforms, Federal Budget submissions and surveys as well as regular communication about contemporary developments health care.

The agenda for CHF is much expanded reflecting the many dimensions of health and wider policy that touch people's lives. In the mid-1980s, the organisation's focus was on three main priorities: health and illness services financing; medicinal drugs; and consumers rights. CHF's current strategic plan commits us to advocating with impact across five key areas: prevention and the social determinants of health; primary and integrated care; health financing and design including private health insurance reform; national medicines policy; and safety, quality and consumer participation.

The current state of health care consumer affairs: a snapshot

Australia has made significant inroads to systematically and strategically incorporate consumers interests into policy and practice. These span many sectors and industries. If it weren't for the leadership of CHF, other consumer organisations and individual consumer advocates, the consumer contribution would be much less advanced. The developments we have witnessed since the mid-1980s include the following.

Valuing the consumer perspective and lived experience

There is clear and growing value placed on consumer insights, advice and lived experience in policy making,

program and service development. Demand for consumer representatives on national committees and in policy roundtables and forums is strong: it is rare to see high level national committees without a consumer member. The case for consumer participation in governance and advisory arrangements is encouraged at all levels. The adoption of frameworks such as the International Association for Public Participation's Spectrum of Engagement or variations of it is also commonplace and this has encouraged a more systemic and strategic approach to consumer participation.

However, co-design, co-production and co-creation are only emergent concepts with the associated practice only just starting to enter our lexicon. , We need to put effort into raising awareness of these methods and translating these approaches into practice. The challenge that also remains is the degree to which consumer expertise is valued and remunerated in the same manner as clinical or research expertise.

Consumer-centred care policy

There is a plethora of principles and terms that convey the intent that health care is primarily about people. Terms such as 'consumer centred care', 'consumer engagement', 'participatory health', 'consumer participation', 'co-design' and 'partnering with consumers' are ever present in national, state and local health policies and plans although variable in the degree they are practised. A chasm between policy intent and these principles being put into practice remains a great risk. There are programs and service models emerging that give effect to these policies of greater control and choice for consumers such as the National Disability Insurance Scheme (NDIS), aged care reforms and patient-centred health care homes.

More structures in place

Consumer and community advisory committees within organisations have been established as well as state-based health consumer organisations. Australia's regional health infrastructure of Primary Health Networks (PHNs) and local hospital networks and districts (LHNs/LHDs) feature an array of different structures and consultative platforms involving consumers – with national guidelines requiring PHNs to have, as a minimum, a community advisory committee. This is indicative of the increased importance and value placed on the consumer voice and the need for health services and organisations to engage with consumers. There is growing evidence and examples

¹ Sources: 1992 PhD thesis of Eileen Baldry, The development of the health consumer movement and its effect on value changes and health policy in Australia, and CHF Annual Reports.

of consumer engagement and participation policies within organisations as well as employment of consumers to drive consumer engagement and peer support. Increasingly, research grants and development of training modules have a requirement to include consumer input and feedback.

Continued spotlight on the safety and quality agenda

Organisations such as the Australian Commission on Safety and Quality in Health Care (ACSQHC) and Safer Care Victoria (SCV) have been established to promote safety and quality in health care and in response to the occurrence of poor and unsafe practices. Mandatory National Safety and Quality Health Service Standards now exist for Australian health care organisations (HCOs) against which all are accredited. These include standards pertaining to patients as partners in care, a standard which commenced as a developmental standard, but which is now compulsory. NPS MedicineWise has established with consumer advocacy and involvement to enable people to make and act on the best decisions about medicines, health technologies and other options for better health and economic outcomes. Consumers are involved in many committees of the Therapeutic Goods Administration (TGA) and several high-level health technology assessment bodies such as the Medical Services Advisory Committee (MSAC) and the Pharmaceutical Benefits Advisory Committee (PBAC). A consumer is Deputy Chair of PBAC.

Influencing research, ethical practice and delivery of care

CHF and the National Health and Medical Research Council (NHMRC) have a Joint Statement on [*Consumer and Community Involvement in Health and Medical Research*](#), updated in 2016, to promote and support consumer and community involvement across all types and levels of health and medical research. Most recently, consumer-driven research was recommended as a priority for the Medical Research Future Fund (MRFF). Consumers have worked with the medicines and medical devices industries to shape and play a role in the implementation of various self-regulatory codes of practice including the Medicines Australia (MA) and Medical Technology Association of Australia's (MTAA) Codes of Conduct. CHF partnered with Medicines Australia to develop the '[*Working Together Guide*](#)' to

provide guidance for collaborative relationships between health consumer organisations and research-based pharmaceutical companies. The consumer perspective has helped shaped the recent [*Australian Consensus Framework for Ethical Collaboration in the Healthcare Sector*](#), a sector-led, government supported initiative.

Big data, digitisation of health care and the Information Age

In the mid-1980s the concept of digital health did not exist. Now we have consumers commanding even greater choice and control over their health enabled by access to information on the internet, access to technology that is enabling mobile digital health services, the development of information gateways to find out information about aged care and mental health services and the advent of a personally controlled My Health Record. We have a National Digital Health Strategy and Framework for Action and a community that is aware that, along with the benefits of digital health developments, comes the risk of breaches of the security and protections that protect their personal information. People have firm views about who owns and how their personal health data is used as reported in a recent CHF and NPS MedicineWise joint study, [*Engaging Consumers in their Health Data Journey*](#).

Training and support for consumers

Consumer advocates have been equipped to act with impact and influence across a range of settings. Training and networking opportunities are available through state-based health consumer peak organisations and other consumer organisations. CHF offers e-learning for representatives we nominate to national committees and has been actively championing new and innovative models for equipping consumers as leaders, running a national demonstration of the Collaborative Pairs program, a program developed in the UK to assist consumers and clinicians/service providers to work in new ways together. Trialling this model in Australia is designed to build capacity of consumers for a new and emerging leadership role.

THE HEALTH CARE HORIZON: THE SHIFTS REQUIRED

The Productivity Commission gave a sobering appraisal on the state of our health system in its 2017 *Shifting the Dial: 5 Year Productivity Review*. Problems highlighted included insufficiently devolved funding preventing locally efficient solutions; insufficient attention to patient experiences and outcomes; weak capacity for partnerships between consumers and clinicians; poor levels of patient literacy; low levels of choice; Commonwealth/state funding splits creating poor incentives to integrate and too many services known to be ineffective or outdated still being funded.

If we are to move to a system where consumers, their carers and families can experience health and social care where these pain points are addressed, transformational shifts are required at the system level, within organisations and in health care settings themselves.

These shifts are essential if consumers are to:

- be involved in all levels of decision-making
- be enabled to make informed decisions and choices about their health care
- feel trusted and respected by service providers, managers and funders
- have access to affordable, co-ordinated and quality health care which is focussed on the whole person
- be engaged in collaborative and partnership approaches to service planning and improvement
- serve as the engine room for improving and innovating health and social care services.

These require the following shifts in policy but, more fundamentally, also in attitudes, behaviours and practices.

System

From illness to wellness

Our current health system is predominantly focused on treating and managing ill-health. Most people don't visit a healthcare provider until they have a symptom or are unwell. Australia faces the problem of managing a rising number of people with multiple chronic conditions or with risk factors for chronic conditions. A significant proportion of all acute hospital activity is related to treating patients with conditions that could have either been treated or prevented through management in primary and community settings. If this trend is not arrested, we will not be able to afford the kind of world class health system we have become accustomed to.

Our health system is no longer fit-for-purpose: we need to recalibrate. The solution to our looming health crisis is to

renew our focus on and investment in preventative health and integrated primary health care in community settings. This recalibration must recognise that many of the drivers of ill health lie outside the health system. This requires a fundamental shift in policy development towards a 'whole of government approach' including urban planning, public transport, and systemic support for healthy lifestyle choices such as food pricing and regulation. Health care that works independently of housing, disability and social services will always be less effective than when these systems work together². It requires us to embrace the prospect of retailers, wellness coaches, pharmacies, insurers and technology companies playing a more significant role in keeping us well³. It requires measures to equip people to be proficient at managing their own health and wellbeing, supported by digitally enabled personalised systems. It

² Ham, C., Dixon, A., Brooke, B. (2012) *Transforming the Delivery of Health and Social Care: The case for fundamental change*. London: The Kings Fund

³ Main, T., Slywotzky, A. (2014) *The Patient-to-Consumer Revolution: How high tech, transparent market places and consumer power are transforming US health care*. USA: Oliver Wyman Health and Life Science

requires us to embrace technological advances that have led to more portable and effective devices for monitoring heart rate, physical activity and blood sugar levels which provide the consumer with readily available data to monitor their conditions. And it requires financing reform at the primary care level to shift us away from fee-for-service arrangements with its perverse incentives for activity and throughput, to a more blended payment structure which enables and rewards quality and preventive health approaches.

From low value to high value

Governments are becoming sharply focused on the need to tackle wasteful spending in health care. A significant share of health care system spending and activities is wasteful at best and harm our health at worst. At a time when health budgets are under pressure worldwide, it

is alarming that around one-fifth of health expenditure makes no or minimal contribution to good health outcomes. Governments could spend significantly less on health care and still improve patient health by making smarter use of health care budgets and stripping out waste. We need less spending on low-value interventions and more on the most effective health activities. Actions to tackle waste are needed in the delivery in care, in the management of health services and in the governance of health systems. Strategies need to include ceasing spending on actions that do not result in value such as unnecessary surgeries and clinical procedures; options for equivalent but lower priced alternatives such as the use of generic drugs; using workforce in different ways such as developing advanced roles for nurses and reorienting the system to ensure that patients who do not require hospital care can be treated in less resource-consuming settings such as general practice⁴, itself operating under financing arrangements that reward value not volume.

From provider-centric to people-centric

The most fundamental shift - and the one that underpins all others - is to reorient our health system to ensure it fundamentally delivers improvements that matter to patients and their changing care needs. We need measures that help us understand whether our health services deliver what matters most to people. Too often we rely on measures of what health systems do, and how much they cost, rather than their effects on patients⁵.

This shift is also about addressing the power imbalance between service providers and consumers. We must place consumers at the core of decisions in health care. People must be empowered to take greater control over their own health care, to influence personalised services and

to take greater responsibility for their health outcomes. There is much in the policy discourse about enabling consumers to participate in the design and monitoring of performance of policies, services and actions which impact on their health and wellbeing. Yet we still have a predominant culture that is about services, organisations and systems determining the direction of service delivery and doing "to", rather than doing "with" or doing "for" people. Effective and safe engagement and participation is a symbiotic not master-servant relationship. Consumers, clinicians and health care organisations can work together and learn and benefit from each other. The very acts of engagement and co-design should deliver activities and results which dispense with power differentials. We need policies that enable, foster and accelerate this practice

From national to local

Australia is a diverse country and our regions have unique characteristics, service architecture and population health profiles. Our demography and geography do not lend themselves to a one-size-fits-all approach to service delivery. We should make the shift to regional budgets for some key areas of health spending where funding is pooled and managed by a single commissioner with flexibility and freedom to commission services to best meet the needs of individuals, families and communities, with those stakeholders engaged as advisers to the processes that determine the best use of those resources. While ever Australia has siloed funding pools, we will struggle to achieve integrated localised services. Elements of such pooling arrangements should include formal agreements between the Commonwealth, the states and territories, PHNs and LHNs/LHDs to improve local and regional system performance and deliver integrated, consumer centred services. PHNs should be progressively empowered to take greater responsibility and accountability for creating primary health care systems in their local areas. This includes broadening the objectives of PHNs and devolving additional funds from the national level to them, with greater flexibility, authority and accountability to commission services based on population health needs supported by consumer codesign. Ideally this shift would see PHNs and LHNs/LHDs working together as co-commissioners of services.

⁴ OECD (2017) *Tackling Wasteful Spending on Health*. OECD Publishing, Paris.

⁵ Ministerial Statement (2017) *The Next Generation of Health Reforms*, OECD Ministerial Meeting, January 2017

Organisations

From low performing to high performing person-centred organisations

Many consumer advocates need to explain and justify their role and organisations, while with good intent, struggle to use consumer advisory arrangements effectively. Remunerating consumers for their time and expertise is also inconsistent across the system and is not always accepted practice. It is commonplace to see only one consumer amidst 12 to 15 other members, none of whom represent the consumer perspective. Consumer participation or engagement is often minimalist, enough to be able to meet a requirement but not substantial enough to demonstrate an impact. Advice and consultation with consumers is often sought too late in the process which minimises impact and influence and standards are not universal in their requirement for consumer engagement and participation. These practices need to change: they keep consumers in a disempowered position and not genuinely a part of strategy-setting and decision-making. Government and other funders should mandate performance and reporting requirements that show evidence of effective and safe engagement and participation of consumers in codesign, service development and monitoring/evaluation. Organisations should be compelled to show how consumer participation has impacted on service delivery, consumer satisfaction and health outcomes, not merely that it has taken place. By the end of the next decade, there must be universal acceptance of the value and legitimacy of consumer as partners in health care at all levels in the system. All health care organisations – no matter their scale - will exhibit the key attributes of high-performing person-centred organisations including comprehensive care delivery; clear purpose, strategy and strong leadership; people, capability and a person-centred culture; person-centred governance systems and person-centred technology and built environments⁶.

From siloed to collaborative, integrated care and governance

People, especially those with chronic, complex and high care needs, value coordinated, comprehensive, multidisciplinary and cross-setting services. Modern health care must feature horizontally integrated health and social care services at regional and local levels. This requires cultural and behaviour change at scale and should be facilitated by national policy frameworks that remove blockages to regional collaborations of clinicians and communities developing local solutions. Actions such as ‘alliance commissioning’ or ‘alliance contracting’ could facilitate the integration of services across traditional primary and hospital care boundaries⁷. Integrated care across systems and sectors will also require integrated governance⁸. Also at issue is how to ensure that clinicians both recognise and ensure a timely response to social issues affecting the health and health outcomes of their patients. It is not the job of clinicians to address the need for safe housing or employment, but there must be the ability to make an instant referral to someone who can address these issues and for the social system to be appropriately responsive⁹. A major shift forward would be to see social prescribing systematically in-built into future models of primary health care and, over time, the prospect of personalised budgets for health care purchasing by people with multiple complex needs.

From information asymmetry to transparency

The information people need to make informed decisions about their health care – both about the services they access and the prices they pay - is often not visible to them, or opaque at best. We need to give people greater agency to exercise choice and control in health care: improved access to information is key to this. The steps required are many and varied and include giving people control over their own health information through

6 Australian Commission on Safety and Quality in Health Care (2018) *Review of the key attributes of high-performing person-centred healthcare organisations*. Sydney, ACSQHC.

7 Jackson C, Gauld R (2018) *Funds pooling in Australia: could alliance contracting hold the key?*, Perspectives Brief, Deeble Institute for Health Policy Research

8 Nicholson C, Jackson C, Hepworth J, Marley J (2017) *Interjurisdictional governance for a health system – is it possible?* International Journal for Integrated Care 2017; 17(3): A 67

9 Russell, L (2018) *Tackling the wicked problems in health by building bridges with social services*: <https://johnmenadue.com/lesley-russell-tackling-the-wicked-problems-in-health-by-building-bridges-with-social-services/>

platforms they can personally control such as My Health Record; acceleration of campaigns such as *Choosing Wisely* to encourage patients to ask questions of their doctor and greater interrogation of and public access to “big data”. Australians pay significant out-of-pocket costs for their health care compared to similar countries and for many families this is a struggle. Greater transparency and more publicly available information about provider credentials, pricing, procedures, facilities and success

rates is needed.

Consumers participating in national committees and local governance arrangements such as PHN and LHN/LHD community advisory committees need access to information and data such as needs assessments, atlas of clinical variation in formats that will enable them to help drive innovation at multiple levels: local service delivery, regional and national and do so from an informed base.

Point of care

From paternalism to partnership

The most significant shift in settings where health care is delivered will be to accelerate changes in the attitudes and behaviours of health professionals and health care organisations away from approaches that many patients perceive as paternalistic towards practices which involve shared decision-making between clinicians and consumers. Professional standards by colleges such as the Royal Australian College of General Practitioners and Standard 2 (Patients are Partners) in the National Safety and Quality Health Service Standards coupled with associated accreditation against these are powerful signals about the behaviours expected. This shift is fundamentally about changing conversations: for clinicians to ask, “what matters to you?”, not “what is the matter with you?” There is also work to be done to encourage and support patients to have the skills

and confidence to be part of shared decision-making conversations. We need to recognise that those with low levels of English language, health literacy and numeracy will need health information in a variety of forms to enable them to participate in decisions about their health. Currently, many health service providers still see themselves as the “expert” and the consumer as a user of a service. Consumers and service providers need to engage in more training and development together to build capacity for shared decision-making and to develop a “dialogue of equals” so the “them and us” culture can be further broken down. The shift from paternalism to partnership can only happen when there is a common value placed on shared decision making and collaborative ways of working.

EIGHT KEY ROLES FOR CONSUMERS

These shifts require strong engagement and involvement of consumers and the community to inform their development and to assure public confidence. The health care consumer of the future – with new found power, agency, activation and access delivered by ever increasing innovation that will disrupt traditional modes of service delivery – will be foremost among the change drivers for a better health system.

Only consumers and their families and carers see and experience the whole health care system. Different clinicians and providers only interact with the system at various windows across the course of their patient’s diagnosis, management and treatment. Consumers’ observations and lived experience can shed a powerful light on how we can improve and reform health care.

Significant advances in the consumer role in health have been seen over the past three decades, but we haven’t fully unleashed the transformative power of consumers. We have seen developments that recognise and value consumer skills and knowledge and create better ways for that to be harnessed yet well-funded industry providers, clinicians and bureaucrats still dominate decision-making. There is a low level of investment in the consumer sector compared to other parts of the health system and lack of accountability to consumers and the community for how and why some decisions are made. There needs to be significant cultural change to rebalance the system to include consumers as equal partners at all points in health care strategy setting and decision making and for them to be at the centre of their health care.

The role of the consumer advocate is not one-dimensional. Consumers fulfil different roles depending on the setting and context in which they work and interact. CHF has identified a typology of eight key roles to describe the many and varied functions fulfilled by consumers and consumer advocates. We have mapped them to where they have greatest relevance at three levels: system, organisation and point of care.

System

Change agents

With the right skills, consumer leaders have the power to transform the healthcare system. They bring insight and wisdom to transform healthcare. They help to frame problems, generate insights, recommend solutions, shift dynamics and stimulate changes and improvements in practice. Consumer leaders can fulfil a variety of roles in national, state and local governance arrangements participating as members, chairs and co-chairs of

Boards and governance committees, sitting on high level policy committees, acting as accreditation surveyors, and serving as members of interview panels for health service organisation staff selection and research grants. Employing consumer leaders in organisations is a new and emerging practice and provides opportunities for peer support roles and building bridges between health professionals and consumers to facilitate attitudinal change and, most importantly, changes in practice.

Policy influencers

Government policy sets out national priorities in health care, signals where major investments are to be made in programs and services and specifies where regulatory effort is to be taken. It is vital that, at this highest level, consumer needs, diversity, knowledge, expectations and experiences are taken into full account. In an environment where community trust in government and authority ebbs and flows as indicated by the recent [Edelman trust barometer](#) and where the imperative on governments is to invest public funds wisely and in accountable ways, they can ill-afford to formulate policies and fund programs that fail to meet the public interest test. In contemporary health care, both clinicians and consumers involved in shaping policy carry stewardship obligations. Direct involvement of consumers skilled in systems thinking and with previous exposure to the policy cycle and associated processes, in policy development through government committees, policy roundtables, in focus groups and other forms of formative research helps them to exercise their stewardship role appropriately as well as helping to shape policy, translate it into implementable programs and services and monitor its impact.

Community mobilisers

Consumers can serve as mobilisers of other consumers to act around a common purpose. In this role they can establish formal or informal consumer networks and organise communities of interest to raise awareness of

health issues, to offer community rating of system deficits and put forward solutions. Many of the now incorporated and well-established consumer organisations that form such a vital part of our national infrastructure and the backbone of CHF's membership are a result of activated consumers stepping up in these kinds of roles. Community mobilisation is another consumer leadership role that is yet to be fully realised and a potent way to tap the sentiment of the wider public and actively and constructively involve them in a discourse about the pain points in the system and the future state of health and social care. We can imagine several innovative ways, enabled by technology and social media, to create and supercharge a social movement akin to Get Up or Aavaz around person-centred health and social care. There will be shifts away from "policy by lobby group" as consumer advocates look for innovative ways to mobilise community sentiment and community groundswell is generated around the direction of health care. Creating a social movement need not be adversarial, quite the opposite, it can be a serious disruptor to the system, a political catalyst and a positive force for change by arming the mobilisers with deep insights from the community about where they want to see change and nudging the system in that direction. Developing local and national consumer and community ambassadors who are articulate and media savvy is also a way to gain public attention and influence governments. This has been demonstrated in other areas such as domestic violence and sexual abuse.

Organisation

Co-designers

Consumers can work with health service planners, providers, clinicians, managers, commissioners and other stakeholders to co-design and co-produce service models, clinical pathways and other projects of mutual interest. The involvement of confident, well informed consumers who are not afraid to challenge and ask questions can help frame the problem to be tackled and identify solutions. User experience ensures first-hand focus on the characteristics of a service or program that will make a difference to a health outcome and the experience of care leading to pathway design or redesign with better awareness of access issues, information required, more humanity and better customer care. With consumers in

the room, others are given permission to explore – what starts out as a service improvement may develop into a major innovation with deeper insights into what will make a difference to consumers. Participation at the same time and on the same footing as service providers and other stakeholders ensures the benefit to individuals and the community is considered in tandem with clinical, management and funding perspectives. Engagement should not end there: enabling consumers to have ongoing roles in the way health services are delivered is also critical to continuously improving and responsive services. Feedback loops such as Patient Opinion and critical friends groups convened by general practices are examples of where real or near time feedback about an experience of service can be facilitated.

Research collaborators

Consumers can add rich insights to research priority setting and assist to frame research questions as well as contribute to the design and methodology. Consumers should be consulted early and often in research from the concept phase of research design, throughout the process. The involvement of consumers and the community in the translation, sense-making and dissemination of research findings is especially potent particularly when the findings are such that a change in public awareness or behaviour is promoted by the results. This also helps drive better policy, health literacy and evidence-based service development.

Educators

Consumers are involved to varying degrees in developing curriculum and modules both for undergraduate and continuing professional education for health care professionals, advising on content relating to the

principles and practices of consumer centred care. Some forays have been made into consumer involvement in the facilitation and delivery of education programs, but this is also in its infancy. This style of educator role – that of developer and deliverer - is emergent and has scope to develop further. Consumers as educators of the next generation of health care providers is an important capability to develop: if cultural change is to occur, then influencing the attitudes and behaviours of undergraduates is a good place to start. CHF's [workforce survey](#) of organisations representing health professionals found high levels of recognition of the benefits of patient-centred care but only 50 per cent of respondents felt their members had access to adequate resources to support a patient-centred approach. Fewer than half said patient-centred care was enshrined in their organisational policy or code of conduct or that their organisation had a patient engagement policy. Experienced consumer advocates are also valued peer educators of emerging consumer leaders.

Point of care

The expert patient

Only patients fully appreciate and know about their condition (s) because it is they who experience and live with it. The expert patient is a person who has the skills, confidence and knowledge to work in partnership with their health care team to make choices and shared decisions about their health care. They have high levels of activation and, as a result, can act and maintain behaviours that achieve improved health outcomes by playing a very active role in their self-management, particularly for those people with chronic and complex conditions.

Payers and contributors

Consumers pay for their health services, procedures and treatments through contributions to the tax base and Medicare levy, by taking out private health insurance (PHI), making private co-contributions where there are gaps between health care costs and Medicare and (PHI rebates, and paying full fee for services not covered by any form of public subsidy. In some areas of care delivery such as disability services, consumers are fund-holders for the services they receive. Consumers have more choice and control of where and how they receive services and from whom through being more active contributors.

RECOMMENDATIONS

There can be no more important an investment than to have an active program for supporting a ready pipeline of consumer leaders. This is essential to their training and development so they are recognised for the skills and knowledge they bring generally but, importantly, so they can function optimally as both partners in their own health, support and treatment decisions and as advocates to have an impact on policy, planning, delivery, evaluation and monitoring. For each of the consumer roles identified we make the following recommendations to support, strengthen and embed these roles.

Change agents

Most organisations invest in the professional development of their managers and clinicians and see this as a valid business expense intrinsic to their workforce strategy. The same view should be taken of consumer leaders and advisers and the same investment made. CHF recommends:

- Access to clinical and corporate governance training for consumer and community members
- A bespoke national consumer and community leadership development program that develops skills in leadership, strategy, project and program management, innovation and design methods, analytical and problem-solving skills, relationship building, facilitation, coaching and presentation skills
- Mentorship programs for established and emerging consumer networks delivered by experienced consumer advocates and linking participants up with mentors from outside the health sector to bring in insights from other industries undergoing transformation
- Innovative learning and development programs such as *Collaborative Pairs Australia*, currently the subject of a national demonstration, to build capacity of consumer and clinical leaders in new ways of working together.

Policy influencers

Consumers are already active and present in government committees, working parties, expert panels and policy roundtables as advocates and representatives. They are often the sole consumer representative among many clinicians and other industry members. We need to create an environment that supports a diverse pipeline of emerging consumer leaders with the skills and

confidence to help develop and drive innovative policy and to do so in a way that represents the views of the wider consumer sector on strategic policy issues.

CHF recommend:

- Host departments and organisations ensure a more balanced ratio of consumer representatives to other members on committees to reflect the heterogeneity and expertise of consumers and adopt policies that consistently and without the need to negotiate, remunerate consumers' time and expertise
- National consumer policy development and leadership training covering the policy and parliamentary cycle, national policy context, service planning and delivery, health technology assessment, research, financial literacy, data literacy, monitoring and reporting
- National consumer advocacy on two or three key policy issues where there is greatest opportunity for influence.

Community mobilisers

Organised networks, communities of interest and social media-enabled platforms are ways to garner consumer sentiment on key health issues to add to insights contributed to national policy debates through more traditional channels. CHF recommend:

- Building [*Australia's Health Panel*](#) to achieve a critical mass and begin to engage the broader community in constructive dialogue on health and social care issues in collaboration with implementation partners with a high number of touchpoints with the community
- High profile community ambassadors who can promote key health issues and influence policy in the public domain
- Local independent consumer and community 'panels' to rate and appraise how health and social care service delivery is tracking, to understand the experiences and concerns of people who use health and social care services and speak out on their behalf to improve people's care like local HealthWatch in the UK

Co-designers

Service development is a key area where consumers can add value as co-designers. Underpinning effective co-design is skills in collaborative practice. This is a new way of working which addresses the power imbalance and helps both service providers and consumers to understand the importance of mutual respect for the role that both perspectives and others play in improving health. CHF recommends:

- Joint training in collaborative practice, experience-based co-design (EBCD), improvement science and methods

Research collaborators

Having more consumers understanding the research process and being involved as key collaborators will help ensure that research in health is meeting the priorities consumers see for health and medical research and that research funding is well directed to community priorities. CHF recommend:

- A national partnership between the Australian Health Research Alliance, CHF and other relevant national bodies to bring together researchers and consumers to build capacity and collaboration in research
- Regional partnerships between research institutes, NHMRC endorsed health research translation centres and consumer groups
- Patient research ambassadors
- Provision of funding to assist consumer participation in research initiatives in competitive research grants
- Routine involvement of consumers in the selection process for research grants.

Educators

Opportunities need to be created for modules on consumer-centred care and the role of consumers in health to be developed, co-designed by consumers. Consumers also need to be equipped to deliver education and training in partnership with health professionals. Such approaches will play an invaluable role in embedding new ways of thinking and working. CHF recommend:

- Partnership between universities, professional associations and CHF to develop undergraduate and continuing professional development modules on consumer-centred care
- Partnerships between CHF and the various health professional associations to systematically include an understanding of patient-centric care in the education and training of new health professionals and to disseminate an understanding of the issues to existing health professionals

- More opportunities and access to interprofessional education and interprofessional collaborative practice and multidisciplinary training and education
- Consumer consultants and peer support workers working alongside health professional students and new graduates in service settings.

Expert patients

Building consumer and community health literacy and supporting patients with the knowledge, confidence and skills to act and maintain behaviours that help them better act on lifestyle risk factors and self-manage chronic conditions is urgently needed. CHF recommend:

- An Expert Patient Program implemented by PHNs and nested in an initiative that combines it with training for clinicians and coaching for practices
- Systematic use of activation measures using validated tools such as the Patient Activation Measure in primary and community care settings to enable GPs and nurses to support patients become expert in managing their condition
- Expansion of *Choosing Wisely Australia* to include a community campaign promoting the 'five questions to ask your doctor'
- More information online and in a variety of health settings that increase health literacy about health conditions, health services and self-monitoring apps
- Access to consumer peer support workers or coaches to assist consumers to understand and navigate the system supported by fit-for-purpose training for peer support workers in coaching and activation skills

Payees and co-contributors

Giving people access to more information about how the health system works as well as greater transparency around health professionals' prices and performance will result in greater agency and capacity to make informed financial decisions about their health care, equipping consumers to play their role as informed payees with reduced information asymmetry. CHF recommend:

- Community education about how Medicare and the private health system works
- Wider publicity about available facilities by health services and general practices
- Information portals that provide an independent evaluation of current market prices for treatments and procedures and clinician outcome data for consumers to compare
- Develop consumer rating tools for health services.

APPENDIX: WHITE PAPER KEY INFORMANTS

Mr Tim Blake, Patient advocate

Mr David Butt, Health Policy Expert and former CEO, National Mental Health Commission

Ms Karen Carey, Consumer

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Ms Melissa Fox, CEO, Health Consumers Queensland

Professor Ian Hickie, Co-Director, Brain and Mind Research Institute, University of Sydney

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Dr Rob Grenfell, Director, CSIRO Health and Security

Ms Debra Kay, Consumer and Chair, Health Consumers of South Australia

Mr Stephen King, Commissioner, Productivity Commission

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