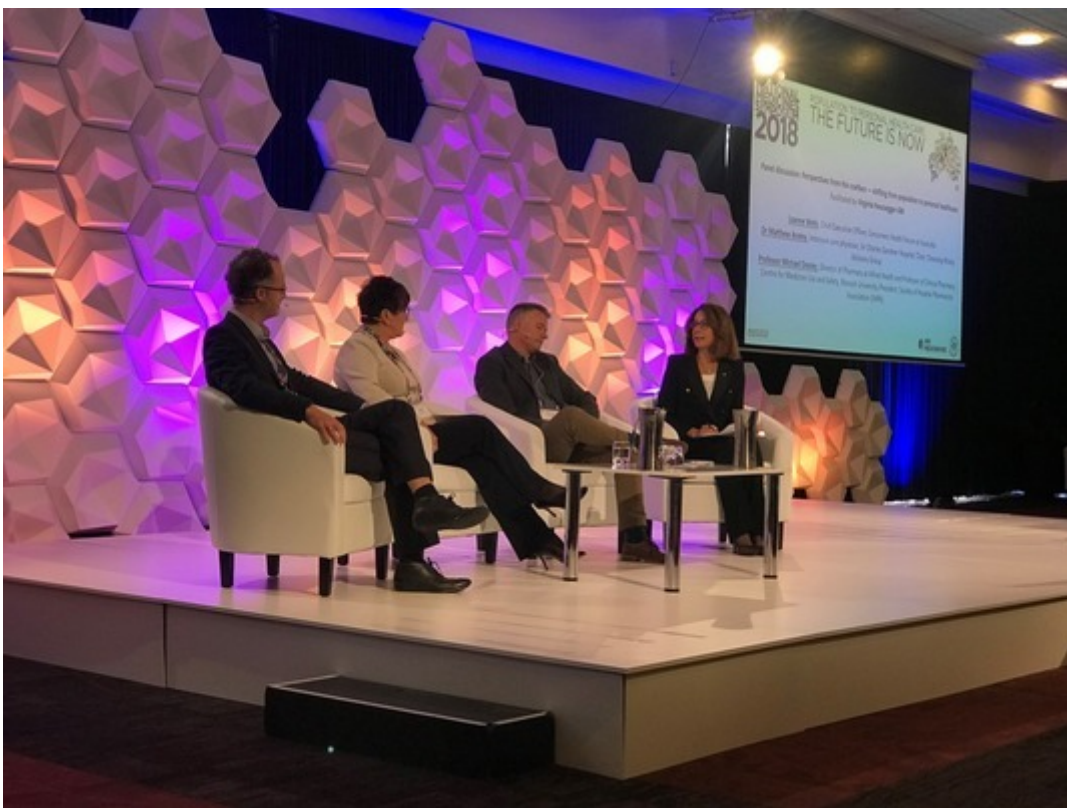


Consumers Shaping Health Volume 12 Issue 2 / June 2018



How Choosing Wisely needs consumers shaping health



Message from the CEO

Events in recent weeks have underlined both the crucial need and widening scope for consumers to be actively involved in design and direction of health policy and services.

At the thought-provoking Choosing Wisely Australia national meeting last week, a key theme was the importance of a continued focus on consumer partnerships. Consumer insights can be powerful forces of change in health care just as technological innovation can be. We need to support consumer leaders and collaborative practice between consumers and clinicians.

However, as I told the meeting, significant efforts are still required to ensure that the promising progress being made by Choosing Wisely Australia is sustained. Along with some other participants, I highlighted the need to address systemic barriers to improving the interactions between health care providers and consumers. There is still a culture in the health system that it's not OK for consumers to question providers,

either because of a belief about their respective roles or just the pressure created by time and financial drivers.

A vital development impacting health care is the use of health data. The *Engaging Consumers in their Health Data Journey* report jointly published by Consumers Health Forum and NPS MedicineWise showed that Australians want control over their health data with 96 percent of Australians believing they should have access to their own health data and 90 percent agreeing they should be asked for permission if either the Government or a private organisation wants to use the data.

My Health Record data will be available on a de-identified basis for use by policy makers and researchers to guide health policies and programs to the benefit of consumers. Consultations that shaped the framework highlighted how important it is for the community to have their health care information kept private with the right protections and safeguards in place.

The need for consumer support and acceptance of our health services is underlined when we consider end of life care. Palliative Care Australia, CHF and Carers Australia have released a Consensus Statement: *Carer and Consumer Engagement in Palliative Care and End-of-Life Care*. The statement highlights the need for palliative care and end-of-life care to be strongly responsive to the needs, preferences and values of people, their families and carers. This statement reflects the growing recognition of the need for all Australians regardless of background or income to have access to quality palliative care when they need it.

There is a pivotal area where we see the need for more consumer involvement and that is in the negotiation of the Community Pharmacy Agreement. The Government in its recently released qualified response to the report of the Government-appointed Review of Pharmacy Remuneration and Regulation, left open the prospect of consumer participation in the next Community Pharmacy Agreements talks. We are urging the Government to include consumers in the process given the widely-accepted view that modern pharmacy needs to shift from its 'dispensing' mentality to one of community care.

The performance of the Government's Health Care Homes trials has come under scrutiny at the latest Senate Estimates Committee hearings with questions about what is happening to the program which the Prime Minister had said would "revolutionise" care. Health Department officials in answer to questions said the pilot scheme had by 16 May enrolled a little under 2,000 patients against a maximum target of 65,000 patients. The hearing was told that the Health Minister had hinted at change to the model. An official responded that the department was not aware of that and was continuing to roll out the scheme and looking at ways to increase patient numbers.

Sadly the health consumer movement has lost an influential figure, Betty Johnson, AO, who worked for many years to promote the place of consumers in health care. [See a tribute to Betty below] Betty represented CHF on a variety of issues, including general practice and health care standards and played an instrumental part in the establishment of Health Consumers NSW. Farewell Betty.

Leanne Wells
Chief Executive Officer

From the Policy Team



It's been a busy couple of months with the Federal Budget brought down in May, and movement on some key areas of policy including community pharmacy and private health insurance. The Budget included a large number of measures across the whole portfolio. Overall our response to the initiatives was positive, although they seemed a bit piecemeal and it was difficult to see a clear vision for the future of the health system. Our [Budget 2018 - Consumer Perspective](#) webinar outlined the key measures from a consumer perspective.



Community pharmacy reforms

In May the Government released the long awaited final report of the Review of Pharmacy Remuneration and Regulation and its response to the recommendations of the review. The review made a range of recommendations aimed at making community pharmacy even more responsive to people's needs. The Government only responded to a few of the recommendations and it essentially keeps the status quo.

CHF believes there is a need for community pharmacy to be reformed. The negotiations for the Seventh Community Pharmacy Agreement will give another opportunity to take these reforms forward. To find out more about our response to the government's views on the review's recommendations go to our [blog](#).



Private Health Insurance

Private Health Insurance continues to be a policy priority with the legislation to enable the reforms announced last year currently in the Parliament. CHF is on the working group looking at improved models of care for mental health and rehabilitation services which is a key component of the next group of reforms. For more information on these working groups including the terms of reference and progress to date [Click Here](#).



Consumers' attitudes to data

In conjunction with NPS MedicineWise, CHF recently released the results of new research about consumers' attitudes to data. The research found that Australians want ownership and control of their own health data and want to be asked for consent when their data is used by either government, private companies or researchers. The comprehensive report was generated through qualitative interviews, literature reviews, a round table discussion with key stakeholders and consumer representatives, and a nationally representative survey of 1,013 Australians. [Click Here](#) to view the report.

Consumer Resources and News



My Health Record

Opt out period announced

The dates for the opt-out period for consumers who don't want a My Health Record created for them by the end of this year have been announced. From 16 July 2018 to 15 October 2018, consumers who wish to opt-out will be able to do so through the [My Health Record website](#) or helpline at 1800 723 471. Form based processes will be available if necessary, however online or on the phone will be the preferred method.

You can register [here](#) to be notified when the opt-out period starts.

Secondary use of My Health Record Data

The Department of Health has released the [Framework to guide the secondary use of My Health Record system data](#).

The secondary uses permitted must be for public benefit and will largely be for public health and research purposes. Insurers of all kinds will not be allowed to access the data, nor will purely commercial uses be permitted. The AIHW will be the organisation charged with managing secondary uses, and no data will be available for secondary uses until they have, with appropriate public consultation, set up the structures and processes needed to manage it.

CHF provided a [submission](#) to the consultation on the framework's development, attended a workshop, and provided a [follow-up letter](#) afterwards.



NSQHS Standards microsite

The new microsite to house all information and resources for the second edition of the NSQHS Standards is optimised to phone, tablet and laptop devices and provides quick and easy access to targeted information for clinicians, consumers, managers and others to support the implementation of the second edition of the standards.

[View the Microsite](#)



Flu Fighters Toolkit 2018

Healthdirect Australia has consolidated Flu content and tools and created a 'Flu Communications Kit'. This communications toolkit is intended to provide individuals and organisations with access to materials that can be used to promote health messages about influenza (flu) across a range of communications channels, including websites, intranets, social media platforms and newsletters.

[View the Toolkit](#)



A holistic approach to palliative care

Palliative Care Australia, Consumers Health Forum of Australia and Carers Australia released the Consensus Statement: Carer and Consumer Engagement in Palliative Care and End-of-Life Care at the National Palliative Care Week Parliamentary Breakfast in Canberra on 22 May. The statement reflects the growing recognition of the need for all Australians regardless of background or income to have access to quality palliative care when they need it.

[View the Statement](#)



Health research and consumers: good thinking

The latest edition of the Consumers Health Forum journal, *Health Voices* focused on the consumer role in health and medical research. It included articles by 15 consumers and researchers who described a variety of projects and approaches involving consumers in design and involvement in research.

[Read Health Voices, May 2018](#)



CHF #withconsumers Tick

Now we have a simple way of showing CHF 's tick of approval. We have introduced the We're #withconsumers tick logo for use in association with activities that CHF believes are supporting authentic health consumers in good practice.

The #withconsumers tick is a means of showing your organisation's commitment to integrating the experience and insight of consumers into your activities.

The tick is available on application for single use where approved, at an event or conference, on a publication, on a website or on material associated with a project or research.

To learn more and apply, [Click Here](#).



Betty Johnson AO (1926 -2018)

Health consumers in Australia have lost a vigorous voice with the passing of Betty Johnson AO, longtime activist and supporter of CHF and co-founder of Health Consumers NSW.

Betty's favourite catchcry was "Nothing about us, without us!" and over her long life she worked with numerous organisations at local, state, national and global level to promote that cause.

She was instrumental in getting Health Consumers NSW, off the ground and was an inaugural Co-Chair and went on to chair HCNSW's Board from May 2012 until October 2016.

Over a period of 15 years from 1994 onwards, Betty was a CHF representative on a range of consumer panels advising the Federal Government and other national bodies. These areas included: General practice projects, the National Health and Medical Research Council, the HealthInsite editorial board and the Australian Council on Healthcare Standards panel on Clinical Governance Research in Health at the UNSW.

She was an energetic representative for older women and, at age 69, Betty attended the 4th UN World Conference on Women in Beijing in 1995. She was a health consumer representative on the Safety and Quality Council (before it became the Commission) and a very active consumer advocate at Northern Sydney Local Health District and Sydney North Primary Health Network, to just name a few.

Betty was made an Officer of the Order of Australia on Australia Day 2000 for her service to the community as a consumer advocate in the areas of aged care and related health issues, to the Older Women's Network (Australia) and to the Australian Pensioners' and Superannuants' Federation.

The first Betty Johnson AO award in partnership with Sydney North Primary Health Network, Northern Sydney Local Health District, and Health Consumers NSW took place in October last year. Health Consumers NSW is working on a yearly remembrance event for Betty.

Some of the many other groups Betty was involved with included Northside Community Forum, NSW Committee on Ageing (now Ministerial Advisory Committee on Ageing), NSW Nurses and Midwives Federation and Home care.

The many significant national and NSW health developments, Betty contributed included: Open disclosure, instigating a culture of safety and quality in healthcare (including the development of the current healthcare standards), hand hygiene and aged care standards.

Her community engagement did indeed reflect her catchcry: Nothing about us without us! CHF extends its condolences to Betty's family, friends and colleagues.

Events and Webinars



Inaugural Youth Health Forum

We are seeking expressions of interest from people aged 16 – 30 who are interested in our kick off Youth Health Forum in Canberra on 18 – 19 September 2018.

[LEARN MORE](#)



Implementation of codeine rescheduling - lessons learnt

We are holding a video conference to discuss the current state of play of the Codeine Rescheduling, on 14 June.

[LEARN MORE AND REGISTER](#)

Consultations and Surveys

Consultation on Draft Decision Support Tool for Osteoarthritis of the Knee

The Australian Commission on Safety and Quality in Care (the Commission) is committed to developing tools and resources for consumers and clinicians to support shared decision making on key health issues. As part of the Commission's work on shared decision making, a [draft decision support tool for patients who have osteoarthritis of the knee](#) has been developed.

Feedback is currently being sought on the draft tool and will be critical to its success and implementation. To learn more and provide your feedback [Click Here](#).

Australian Commission on Safety and Quality in Health Care: Review of the Australian Charter of Healthcare Rights

The Australian Commission on Safety and Quality in Health Care (the Commission) is undertaking a Review of the Australian Charter of Healthcare Rights. A survey has been developed for the purpose of open public consultation to gather as much feedback as possible from the Australian community. The results of this survey will be used to develop the next version of the Australian Charter of Healthcare Rights. To access the survey [Click Here](#).

Monash University Survey on Expectations in Healthcare Testing

Monash University are currently undertaking a sociological study which aims to 'understand the sociocultural processes underpinning optimism for the use of testing

technologies in healthcare'. As part of this project, Monash University are currently seeking volunteers to participate in a short online survey, with the option to participate in a follow up interview on their experience with healthcare testing and screening in Australia. To learn more and access the survey [Click Here](#).

Media

Out of pocket costs have again bounced back as a key health issue in the media. In the wake of our own [Out of Pocket Pain survey report](#), an investigation by ABC's 4Corners program reignited the issue with examples of patients facing many thousands of dollars in medical bills. The program has aroused stronger interest in the scale of medical fees and adds support to the CHF proposal for an authoritative website to list specialists' fees. The issue generated several calls from radio and television seeking CHF's views. There was no shortage of other issues of significance for health consumers in the period. Among other key topics which prompted CHF to reach out to media were: the Federal Budget, the move to opt out for My Health Record, a consensus statement on quality palliative care and the Government's response to the Review on Remuneration and Regulation of Pharmacy. Leanne's media mentions during the period included: [Public patients waiting twice as long for elective surgery](#), [hospitals data reveals](#), [My Health Record opt-out date announced](#), [Opt-out period for My Health Records announced](#)

Recent Media Releases

Media Releases for the period included:

[Out of pocket costs undermining health system](#)
[Health report confirms: consumers want control of their own health data](#)
[Holistic approach to palliative care required for consumers and carers](#)
[Prescription for pharmacy talks: add consumers](#)
[Decision time approaches on My Health Record](#)
[Health funding boost welcome but more needed for primary care](#)
[Australia's Health Panel: your chance to influence the health system](#)
[Aged care reforms require robust support](#)

For a full list of our Media Releases see chf.org.au/media-releases.

Recent Blogs

[An important overview of the pros, cons and questions about My Health Record](#)
[Have your say: time for consumers to be "makers & shapers" in health care, not just "users & choosers"](#)
[Private health care in Australia: health policy's wicked problem](#)

Benefits of Becoming a CHF Member

As a member of CHF you will be kept up to date on key health reform issues through our publications and member alerts. CHF membership enables you to influence the national health agenda by contributing to CHF surveys and polls, consultations and campaigns. Members can draw on CHF position statements, media releases and policy submissions to inform your work and advocacy.

[Find out more about membership here.](#)

Change which emails you get from CHF [here](#).

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