



Private Healthcare Australia
Better Cover. Better Access. Better Care.



National Consumer Engagement Strategy

PHA Submission

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Contact:

Ben Harris – Director Policy and Research

0418 110 863

ben.harris@pha.org.au

About Private Healthcare Australia

Private Healthcare Australia (PHA) is the Australian private health insurance industry's peak representative body. We have 24 registered health funds throughout Australia as members and collectively represent 98% of people covered by private health insurance. PHA member funds provide healthcare benefits for 14.6 million Australians.

Response

PHA welcomes the draft National Consumer Engagement Strategy for Health and Wellbeing. PHA supports the overall purpose, vision and aim of the Strategy.

- The purpose of the Strategy and/or the target audience is clear,
- The objectives for the Strategy are clear and appropriate, and
- The Guidelines describe what is needed to help policy-makers work effectively with consumers, and are explained in a way that makes them useful.

Fundamentals

The Fundamentals do not fully capture the essential elements of consumer engagement.

There are two key elements missing – natural gaps in opinions between consumer advocates and the general public, and industry-sponsored “astroturf advocacy” groups.

Gaps between advocates' positions and general public views

The first is the gap between consumer advocates' positions and overall consumer positions. The majority of people who use the health system do not identify as sick; they just need services occasionally for the purpose of maintaining their health and preventing illness. This majority does not get involved in consumer advocacy.

The fundamental gap is often that the general population are more likely to prioritise cost of living while health consumers' advocates will prioritise access to care regardless of cost. This is a natural effect as interested people are more likely to be heavily engaged in issues. Similar to the regulatory capture effects cited in the academic literature, consumer organisations centred around particular disease groups are likely to be strong advocates for greater investment, research and public spending than the general public. If this bias is not taken into account, it can inappropriately influence decision-making in favour of treatment and more complex interventions, even when the clinical evidence suggests this is not appropriate. This problem can also result in a lack of funding for preventive health measures.

The relative strength of interested advocates and disinterested consumers also needs to be considered. Many areas of health care need strong advocacy, given the lack of attention in the general community. If that advocacy is particularly effective or particularly weak, the preferences of the general community can be distorted.

Within health care, the different capacities of consumer advocacy result in significant issues. Well-resourced consumer groups can take attention away from causes that may be more deserving from a public policy lens. For example, it is easier to gather resources for sick children than for older people, and disease-specific treatment advocacy can be prioritised over effective preventive strategies.

People who are either personally affected by an issue and/or paid to represent a position are much more likely to invest in developing their arguments than those who are not affected. This can result in consumer advocacy being concentrated where the money is, and/or where there are many people

affected and able to effectively advocate. On the latter point, many consumers and carers are struggling too much with their health issues to be in a position to be able to advocate effectively – the characteristics of the disease may be a significant factor in how much consumer effort is left to actually advocate rather than manage the day to day.

When engaging consumers in policy making, it is important to recognise the natural distortions that may occur between advocates' positions and that of the general public. Professional consumer advocates can use the tools of regulatory capture as effectively as industry (see, for example, Salteri et al 2022, [Science: the endless frontier of regulatory capture](#)).

Using broad consumer polling, focus groups and citizen juries is also strong protection against consumer capture. The opinions of the disinterested are often hard (and expensive) to gather, but are an invaluable policy tool. When policy changes are significant to the community, or involve a large transfer of wealth, policy makers should ensure the views of consumer advocacy groups are complemented by broader public views.

“Astroturf advocacy” and consumer groups

The second gap in the fundamentals is much more insidious – the rise of astroturf consumer groups almost completely funded by industry. [Purdue is most \(in\)famous for this](#) in the health arena, funding a range of patient advocacy groups to promote the overuse of its opiate pain medicine Oxycontin. The fact this resulted in tragedy is well-documented.

In [Poisoning the Well: How Astroturfing Harms Trust in Advocacy Organizations](#), Edwards and Le (2022) note,

[Astroturfing] “is a strategy in which an organization ventriloquizes political claims-making through the channel of seemingly independent activist groups. Astroturfing—that is, faking the appearance of grassroots support—can be defined by three characteristics: when a sponsor masquerades as a mass movement, engages in fraudulent claims-making, and/or provides heavy (often material) incentives to everyday activists to support their interests.”

There are a range of so-called consumer groups in both the pharmaceutical and medical device markets across Australia which may show signs of astroturfing. Such organisations appear to be very small, with one or two staff and limited membership, yet have significant corporate sponsorship and make sophisticated proposals to government agencies (including MSAC and PBAC) supporting industry positions.

When seeking consumer representation, transparency is vital. Policy making bodies should ensure all consumer organisations routinely declare their membership, funding mix and other corporate support so the legitimacy of the views put forward can be properly assessed.

Toolkit

The Toolkit will be easy to use and will help policy-makers better engage consumers in policy-making. However, it would be improved with greater emphasis on transparency and declarations from consumers and consumer organisations.

Conclusion

The National Consumer Engagement Strategy for Health and Wellbeing represents an important and much needed shift towards ensuring policy makers engage more effectively with consumers to deliver measures that improve the health and wellbeing of the Australian population.

However, to achieve this goal, due consideration must be given to the needs of the general population to make sure they align with the position of consumer advocates, and also importantly to curb the rise and undue influence exerted by astroturf advocacy groups in the Australian health system.