

NATIONAL MEDICINES SYMPOSIUM (NMS) 2018

Consumer representatives' report

Independent, not-for-profit and evidence-based, NPS MedicineWise enables better decisions about medicines, medical tests and other health technologies. NPS MedicineWise receives funding from the Australian Government Department of Health.



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Acknowledgments

NPS MedicineWise extends its sincere appreciation to all the consumers who contributed to this report, and in particular to Debra Leticia and Melissa Cadzow, who volunteered their time to participate in the National Medicines Symposium (NMS) 2018 and to craft this report.

Melissa and Debra would like to congratulate and thank Dr Lynn Weeks AM, Chief Executive Officer of NPS MedicineWise at the time of NMS 2018, and all staff at NPS MedicineWise for making us as Consumer Rapporteurs feel so welcome and valued, and ensuring our voices were heard. Melissa and Debra would also like to thank consumer representative and former NPS MedicineWise board member Debra Kay for her support, encouragement and guidance before, during and after NMS 2018.

National Medicines Symposium (NMS) 2018: Consumer representatives' report

NMS 2018: From population to personal health care – the future is now

NPS MedicineWise hosts a National Medicines Symposium (NMS) every two years. NMS 2018 was the 10th NMS and was held in Canberra on 30 May and 1 June 2018. Delegates included clinicians, policy makers, researchers and academics and industry, consumer and government representatives. The program and media releases can be seen at nps.org.au/nms2018 and nps.org.au/media.

NPS MedicineWise

NPS MedicineWise (nps.org.au) is an independent, not-for-profit, evidence-based organisation. It achieves better health and economic outcomes by enabling people to make the best decisions about tests, treatments, medicines, technologies and other medical choices. NPS MedicineWise programs include Choosing Wisely (choosingwisely.org.au), Medicine Insight (nps.org.au/medicineinsight) and the [MedicineWise App](#).

This consumer report from NMS 2018

NPS MedicineWise works in partnership with the Consumers Health Forum of Australia (CHF – chf.org.au). CHF recruited two consumer representatives to be Consumer Rapporteurs for NMS 2018: Ms Debra Letica and Ms Melissa Cadzow. Their role was to document consumer perspectives on the symposium activities, outcomes and recommendations. The consumer perspectives contained in this report are not necessarily those of the rapporteurs themselves, and might reflect those of other consumers at NMS.

Consumer keynote address from Susan Morris, Lynch Syndrome Australia *Misdiagnosed, misunderstood, missing out: the journey for many.*

This year, a consumer keynote speaker, Ms Susan Morris from Lynch Syndrome Australia, closed the conference with a powerful presentation of her personal journey - and implications for health professionals and services. In doing so, she emphasised that communication needs to demonstrate a partnership between the patient/consumer and clinician: *there is no place for parental style health care anymore*. Susan said that consumers want assurance and hope, to be heard and cared for at one of the most vulnerable times in one's life. She mentioned that much is lost in translation and that we can get caught up in mortality rates, data and standard of care protocols. There is a "gap" in health care that many fall through. Being told you're in that "worried well" group or that you're "overly passionate" is not helpful. These types of comments alienate consumers/carers and build barriers that impeded the building of collaborative partnerships. NMS closed with Susan's message: the new revolution in health care is that consumers really are partners in the health care team.

20 key consumer perspectives from NMS 2018

1. Care must encompass trust and respect with consumers as equal partners in health care
2. Data has value: collection of consumer data is not an end in itself
3. We need to get better at the good news stories
4. Systemic collection of patient experience is an important teaching tool
5. Kindness is the key to enabling conversations about what is important to the consumer
6. Keep asking the patient what matters to them and what outcomes they are after
7. Avoid creating silos in digital health

8. Individual and environmental health literacy remain a high priority for consumers.
9. Plan for future health care wishes and end of life; increase awareness and do this better
10. Keep the focus on better outcomes
11. We cannot afford to lose the “human element” in the journey of health care evolution
12. In the digital transformation of healthcare, it’s not about the technology - it’s about delivering better patient outcomes
13. Build collaborative partnerships via primary health and social care
14. Get the right players together, including consumer representatives, so we can work together to build innovative systems, policies and practices. We are all health reformers.
15. Develop clinical and cultural competency in a fast-changing world – through co-design
16. Attend to everyone’s wellbeing; the health and wellbeing of clinicians is important too
17. Ensure patient-centred care is embedded at every level
18. Co-design via consumer engagement at every stage of the process, sharing responsibility for design, implementation and translation so our work is relevant to consumers and communities
19. Encourage consumers to follow up on the NMS 2018 program (nps.org.au/nms2018) and media releases (nps.org.au/media).
20. Build on the rapporteur role at NMS 2020 and other conferences to ensure consumer perspectives inform not only the planning of events but also the analysis and recommendations

In summary

NMS 2018 was very positive, with appropriate emphasis on potential benefits and risks of medical interventions. The symposia are very relevant to consumer representatives. We look forward to a co-designed NMS 2020.

Further information contact NPS MedicineWise on info@nps.org.au

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