

# PROMOTING PATIENT BASED CARE AND CONSUMER ENGAGEMENT

## Karen Luxford

Clinical Excellence Commission NSW, Sydney, New South Wales; Quality and Clinical Effectiveness Advisory Committee, Cancer Institute NSW, Eveleigh, New South Wales.  
Email: karen.luxford@cec.health.nsw.gov.au

## Abstract

Consumer engagement has blossomed in recent decades into a comprehensive approach, not only engaging people in their own care, but also in key health care system improvements at a range of levels including health services, research, governance and policy. These changes parallel international progress in patient based care and culminate in the recognition of the need for consumer partnerships in recent national and state frameworks. Striving to deliver patient-based care means that we need to rise above the 'disease-based' model of care. Consumer engagement to improve Australian cancer care has grown to support all aspects of the journey.

"Why would you want a consumer on the guidelines working group? This is about best clinical practice. We know the research evidence," said the doctor. That statement was delivered over 15 years ago now. How things change! Recognising the importance of the patient's perspective and engaging consumers in all levels of activity in health care has come a long way in Australia in a relatively short period of time.

While promoting consumer engagement in health care has been a more recent development, its origins can clearly be linked to grass-roots community engagement movements in the 1960s and 1970s and public engagement (particularly by UK governments) in the 1980s and 1990s. Initially, patient engagement in health care focused on individual patients and centred on 'self-management' of chronic conditions and 'shared decision making' for treatments. Equally, the broader social rights movement can be seen to have generated a focus on 'patient rights'. In 1987, Consumers Health Forum of Australia was established to champion consumer issues. Prominent advocacy groups started to form centred on specific diseases such as HIV-AIDS and cancers.

Australia was recognised early on as leading the way for the world in consumer advocacy. Starting in the late 1980s, researchers worked to identify core components of 'patient-centred care', and in 1993 The Picker Institute (US) identified eight domains: respect for patient preferences and values; emotional support; physical comfort; information, communication and education; continuity and transition; co-ordination of care; involvement of the family and friends; and access to care.<sup>1</sup> It was acknowledged that really understanding patient values and preferences required establishing a healing relationship between clinicians, patients and patients' families, grounded in strong communication and trust.<sup>2</sup> By 2001, recognition of 'patient-centredness' as an essential characteristic of high quality care by the US Institute of Medicine, cemented patient focus as a key domain of quality.<sup>3</sup>

Against a background of high profile inquiries in Australia highlighting harm to patients and the need improve patient safety,<sup>4</sup> consumer engagement has increasingly focused on improving care delivery and on governance. Patient involvement has been recognised as a way to deliver safer care for individuals and to improve accountability in the health services, but requires a shift from provider-focused 'paternalism',<sup>5</sup> to 'patient empowerment'.

## Recent innovation

Within the last six years, a growing body of evidence has emerged indicating that patient-based care – with patients as true partners – not only improves the patient care experience, but also results in clinical and operational-level benefits. This growing evidence includes decreases in mortality,<sup>6,7</sup> rates of hospital-acquired infection,<sup>8</sup> surgical complications,<sup>9</sup> and improvements in patient functional status,<sup>8</sup> and higher quality clinical care.<sup>10</sup> The business case for patient-focused care highlights decreased malpractice claims, decreased staff turn-over, reduced operating costs and increased market share.<sup>11</sup> Leading health care services are those that are transforming their care delivery with a focus on patient and consumer engagement at all levels – from the ward to the Board.<sup>12</sup>

A systematic review by Doyle et al.<sup>13</sup> has also highlighted the positive association between self-reported patient experience, clinical outcomes and resource utilisation (eg. impact on length of stay). Increasingly, patient feedback is being used at a service and systems level to drive patient-focused approaches to quality improvement, evidenced in Australia by state-based surveys of cancer patients. For example, when the Cancer Institute NSW conducted its inaugural patient experience survey in 2007, 'discussing anxieties and fears' and 'pain management' stood out as key aspects of care for improvement.<sup>14</sup>

Patient narratives and stories are also acknowledged as powerful drivers of change. The shared stories of people living with cancer have provided great insights and

motivated us to aim to 'get it right'. Sharing his story of a diagnosis of prostate cancer, Ian Roos encapsulated the journey through diagnosis and treatment choices for many cancer patients – fear of cancer, confronting mortality, quality of life choices and the question of 'why me'?<sup>15</sup>

Over the past 40 years, since the Clinical Oncological Society of Australia (COSA) was established, consumer engagement in cancer care has blossomed into a comprehensive approach, not only engaging people in their own care but also in key health care system improvements at a range of levels including health services, research, governance and policy. Australia has a proud history of consumer engagement and advocacy in the cancer field. Early leading groups included Breast Cancer Advocacy Groups (Vic – 1994 and NSW - 1997), Prostate Cancer Foundation of Australia (1996) and Breast Cancer Network Australia (1999). CanTeen was developed in 1985, advocating for young people with cancer.

'Nothing about me without me',<sup>16</sup> – the catch phrase for improving the quality of healthcare by involving patients – exemplifies the approach used in Australia. Early efforts in consumer engagement ensured that Australian cancer care focused on a comprehensive view of care delivery – 'the whole journey'. The prominence of psychosocial care for cancer patients was driven by consumers and resulted in the world's first guidelines in this area, released by the National Breast Cancer Centre.<sup>17</sup> Cancer consumer groups helped identify crucial issues to be addressed – talking about cancer, breaking bad news, support for partners and children, palliative care and survivorship. Consumers also helped clinicians to consider guidance on subject matter that they were typically not comfortable with – the 'no treatment' option and alternative and complementary therapies. Issues for younger cancer patients came to the foreground in consideration of fertility preservation before cancer treatment and treatment during pregnancy. With the increasing successes of treatments for a range of cancers, came the question of how to support people living with the longer term sequelae of those treatments. Personalised, tailored therapies appeared on the market, with evidence of improved survival rates. Consumers mortgaging their homes reminded us that these new therapies often came with a price tag. In areas where services were perceived as lacking, cancer advocacy groups lobbied for increased access to health services (eg. radiotherapy).

## Consumers and cancer research

Aligning research priorities with consumer priorities is another area where Australian consumer groups have shown leadership. The 'Consumer Involvement in Research Program', initiated by Cancer Voices NSW in 2002 in partnership with Cancer Council NSW, has supported consumer engagement through training and 'match making' consumers with research programs – either as advisors, grant reviewers or investigators. More broadly, cancer consumers have been involved in helping to identify priorities for future research across the patient journey continuum,<sup>18</sup> and ensuring that consumer-friendly websites about clinical trials are available.

COSA has also contributed to promoting consumer engagement in clinical cancer research. Through the 'Enhancing Consumer Engagement in Clinical Cancer Research' project, funded by Cancer Australia, COSA has focused on developing a comprehensive strategy for increased consumer involvement at all levels of clinical cancer research, through increased training, mentoring and collaboration across the 14 Cancer Cooperative Trial Groups.

## Assume nothing

Consumers have taught us the importance of 'assuming nothing'. Assumptions can lead to "patient preference misdiagnosis".<sup>19</sup> This gap between 'what patients want' and 'what doctors think patients want' is illustrated by a study of the views of breast cancer patients.<sup>20</sup> Although doctors believed that 71% of patients with breast cancer would rate keeping their breasts as a top priority, only 7% of patients rated this as their top priority. Similarly doctors thought that 96% of breast cancer patients considering chemotherapy would rate living as long as possible as a top priority, when in fact only 59% agreed.

This lesson of 'assuming nothing' has extended into the cancer consumer groups with the acknowledgement that 'cancer patients' are not one amorphous group. Rather, in the broad multicultural community of Australia with different cancer profiles, there has been increasing recognition over recent decades of the need to hear voices from a range of cancer survivors. The challenge to engage 'hard to reach' consumers continues, particularly in the Indigenous and culturally and linguistically diverse communities, as evidenced by the work of CanNET Victoria, supported by Cancer Australia.<sup>21</sup>

The need to support cancer consumers with science and advocacy training was also identified early on in Australia, with a program developed in the late 1990s by the National Breast Cancer Centre in collaboration with Breast Cancer Network Australia. Consumers having attended training were then supported to engage in decision-making forums and committees through the Breast Cancer Network Australia's 'Seat at the Table' program.

As synergies among the cancer consumer groups and their priority issues emerged, Cancer Voices formed in most Australian states, initially in NSW (2000), culminating in the establishment of Cancer Voices Australia in 2006.<sup>22</sup> These organisations work at a range of levels, ensuring that the voices of people affected by cancer continue to be heard and consumers are engaged across the spectrum.

## Frameworks and standards

Working in partnership Cancer Voices Australia, and Cancer Australia developed a '*National Framework for Consumer Involvement in Cancer Control*'.<sup>23</sup> Released in 2011, this framework identified key elements to help guide organisations to engage consumers. The framework highlighted four essential elements for effective cancer consumer involvement: committed organisations; capable consumers; inclusive groups; and shared focus. The framework's approach to consumer participation builds on

Popay's model for community engagement, which is widely used internationally.<sup>24</sup> The framework will be accompanied by resources tailored for a range of professions to further support engagement.

In 2011, the Australian Commission on Safety and Quality in Health Care released a national discussion paper on '*Patient Centred Care: improving quality and safety through partnerships with patients and consumers.*' This paper summarised international initiatives and research evidence about partnership approaches to improving quality health care.<sup>25</sup>

Moving beyond discussion, the commission's *National Safety and Quality Health Service Standards* have devoted an entire standard to 'Partnering with consumers',<sup>26</sup> with engagement of consumers of health services being integrated throughout the remaining standards. This new system for accreditation of health services came into effect across Australia on 1 January 2013.

## Rising to the challenge

In recognition that an organisation-wide approach is required to transform care for a greater patient focus, the Clinical Excellence Commission released 'The Patient Based Care Challenge' in NSW, promoting strategies for engaging patients, families and carers at all levels within health care services.<sup>27</sup> Rising to the challenge of transforming health care sees services undertaking engagement in strategic planning, quality improvement and assurance, staff education and employment selection, utilising patient feedback, through to involvement in bedside handover and activation of medical emergency teams. The Chris O'Brien LifeHouse at Royal Prince Alfred Hospital is the first cancer-specific service to sign up to The Patient Based Care Challenge in NSW.

Striving to deliver patient-based care means that we need to rise above the 'disease-based' model of care that we inherited in the 18th Century and move beyond the military model of care delivery that dates back to ancient Rome.<sup>28</sup> Tanya Hall's 2012 article, entitled 'More than the sum of our parts',<sup>29</sup> challenged us to see some of the present deficiencies in cancer care too often focused on "pathology at the expense of the person". While acknowledging receipt of excellent medical care, Hall was "surprised and dismayed by the lack of basic humanity and courtesy from some of the health professionals I encountered." Her concluding advice to health care professionals is to "try, always, to look beyond the diseased part you are treating to the person underneath. Perhaps then the rhetoric of patient-centred care can begin to approach reality."

Thinking back over the decades, consumer engagement to improve Australian cancer care has grown to support all aspects of the journey and become a mainstream approach particularly, at a systems and policy level. I recall reflecting on how far things really had come when in more recent years a doctor said to me, "Obviously, we will have a consumer included on this working group. We couldn't do it without them." We have come a long way.

## Acknowledgements

The author acknowledges the input of Sally Crossing and Ian Roos in the preparation of this article. Their work and that of many other people living with cancer inspires us all.

This article is dedicated to Emeritus Professor Tom Reeve – wise mentor and champion of consumer engagement in cancer care.

## References

1. Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL (eds). *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care*. San Francisco: Jossey-Bass, 1993.
2. Epstein RM, Fiscella K, Lesser CS, Stange KC. Why the Nation Needs a Policy Push on Patient-Centered Health Care. *Health Aff (Millwood)*. 2010; (29)8:1489-95.
3. Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Committee on Quality of Health Care in America, Institute of Medicine, Washington, DC, USA: National Academies Press, 2001.
4. Joint Select Committee on the Royal North Shore Hospital. *Report on Inquiry into the Royal North Shore Hospital*. Sydney: NSW Legislative Council, State of New South Wales, 2007.
5. Donaldson L. The challenge of quality and patient safety. *J R Soc Med*. 2008;101:338-341.
6. Meterko M WS, Lin H, Lowy E, Cleary PD. Mortality among patients with acute myocardial infarction: The influences of patient-centered care and evidence-based medicine. *Health Service Research*. 2010;45(5):1188-1204
7. Glickman SW, Boulding W, Manary M, Staelin R, Roe, MT, Wolosin RJ et al. Patient satisfaction and its relationship with clinical quality and inpatient mortality in acute myocardial infarction. *Circ Cardiovasc Qual Outcomes*. 2010;3(2):188-195.
8. DiGioia AM. The AHRQ Innovation Exchange: Patient- and family-centered care initiative is associated with high patient satisfaction and positive outcomes for total joint replacement patients. Agency for Health Care Research and Quality. 18 December 2008.
9. Murff HJ, France DJ, Blackford J, Grogan EL. Relationship between patient complaints and surgical complications. *Qual Saf Health Care*. 2006;15:13-16.
10. Jha AK, Orav EJ, Zheng J, Epstein AM. Patients' perception of hospital care in the United States. *N Engl J Med*. 2008;359(18):1921-31.
11. Charmel PA, Frampton SB. Building the business case for patient-centred care. *Healthcare Financial Management*. 2008;March:1-6.
12. Luxford K, Safran D, Delbanco T. Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. *Int J Qual Health Care*. 2011;23(5):510-515.
13. Doyle C, Lennox L, Bell D. A systematic review of evidence on links between patient experience and clinical safety and effectiveness. *BMJ Open* 2013;3:e001570. doi:10.1136/bmjopen-2012-001570.
14. NSW Cancer Patient Satisfaction Survey. Cancer Institute NSW, Sydney, 2007.
15. Roos, I. Reacting to the diagnosis of prostate cancer: patient learning in a community of practice. *Patient Educ Couns*. 2003;49:219-224.
16. Delbanco T, Berwick DM, Boufford JI, Edgman Levitan S, Ollenschlager G, Plamping D et al. Healthcare in a land called PeoplePower: nothing about me without me. *Health Expect*. 2001;4(3):144-50.
17. Clinical practice guidelines for the psychosocial care of adults with cancer. National Breast Cancer Centre, Sydney, 2003.
18. Saunders C and Crossing S. Towards meeting the research needs of Australian cancer consumers. *BMC Research Notes*. 2012;5:667.
19. Mulley A, Trimble C and Elwyn G. Stop the silent misdiagnosis: patients' preferences matter. *BMJ* 2012;345:345-351.
20. Lee CN, Hulsman CS, Sepucha K. Do patients and providers agree about the most important facts and goals for breast reconstruction decisions? *Ann Plastic Surg*. 2010;64:563-536.
21. The development of a consumer participation strategy for difficult-to-access consumers in the NEMICS and Hume RICS geographic areas. Prepared by Health Issues Centre for CanNET Victoria (Cancer Australia Initiative), 2009.
22. A Decade of Success. *Cancer Voices NSW, 2000-2010*. Cancer Voices NSW, Sydney, 2011.
23. Cancer Australia and Cancer Voices Australia. *National Framework for Consumer Involvement in Cancer Control*. Cancer Australia, Canberra, ACT, 2011.
24. J. Popay. *Community Engagement, community development and health improvement*. A Background Paper prepared for NICE, 2006.
25. Australian Commission on Safety and Quality in Health Care. *Patient-Centred Care: Improving quality and safety by focusing care on patients*

- and consumers. Australian Commission on Safety and Quality in Health Care, Sydney, 2010.
26. Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards. Australian Commission on Safety and Quality in Health Care, Sydney, 2011.
27. Clinical Excellence Commission. The Patient Based Care Challenge. CEC, Sydney, 2010.
28. Luxford K. The forgotten tenet: client focus and quality improvement in health care. *Building Quality In Health Care*. 2010;4(2):10-12.
29. Hall TL. More than the sum of our parts. *Med J Aust*. 2012;197(9):522-523.

## PSYCHOSOCIAL ASPECTS OF DELIVERING CANCER CARE: AN UPDATE

**Phyllis Butow,<sup>1</sup> Afaf Girgis,<sup>2</sup> Penelope Schofield.<sup>3</sup>**

1. Psycho-Oncology Co-operative Research Group and Centre for Medical Psychology and Evidence-based Decision-Making, School of Psychology, University of Sydney NSW, Camperdown, New South Wales.
2. Department of Nursing and Supportive Care Research, Peter MacCallum Cancer Centre, Victoria, Australia, and Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne, Victoria, Australia.
3. Ingham Institute for Applied Medical Research, South Western Sydney Clinical School, University of New South Wales, NSW, Australia
- Email: phyllis.butow@sydney.edu.au

### Abstract

Cancer patients face psychological and physical challenges after diagnosis, and can benefit greatly from appropriate psychosocial care. This paper presents a brief history of psychosocial oncology care and recent developments in Australia. Consumers, doctors, nurses, allied health and psychosocial health professionals have all played an important role in this area. Some highlights include: the Australian psychosocial clinical practice guidelines; the development of key patient reported outcome measures; documentation of stress and burnout in oncology health professionals; the development and evaluation of communication resources; a recent focus on survivorship; and a growing body of intervention research which is aiming to be clinically feasible and implementable. The Clinical Oncological Society of Australia hosted the first psycho-oncology professional group in Australia, supporting the development of psychosocial guidelines for adolescents and young adults and undertaking key work in survivorship and rural issues.

Cancer patients face practical, emotional and psychological demands in addition to the physical effects of their disease and treatment. Challenges include existential fears following diagnosis with a life-threatening disease, treatment decision dilemmas, pain, discomfort and functional impairment associated with the disease and its treatment, and body image changes associated with cancer treatment. A cancer diagnosis can impact on patients' physical and psychological health, sexuality, finances, relationships and ability to continue in roles at home and work.<sup>1</sup> Further, the disease affects not only the patients, but their families and carers, who can experience as much or greater distress as the patient themselves.<sup>2</sup>

The number of people diagnosed with cancer in Australia is set to increase from just over 100,000 per annum in 2012 to 150,000 by 2020. Efficient, effective and clinically feasible supportive care interventions are required to both reduce morbidity in this growing population, as well as assist in preventing the high rate of burnout reported by front-line oncology staff.<sup>3</sup> This article will present a brief history of psychosocial oncology care in Australia and describe recent developments within the field, highlighting Australian achievements, and the important role that

the Clinical Oncological Society of Australia (COSA) has played.

### Establishing psycho-oncology

Psychosocial care is broadly provided in Australia by specialist psychosocial staff (psychiatrists, psychologists and social workers), as well as front-line medical, allied health and nursing staff in oncology and palliative care. While social work has had a significant and ongoing role in oncology since the beginning of the 20th century,<sup>4</sup> psycho-oncology is a relatively young discipline internationally, emerging only 40 years ago in Europe and the US. In Australia, the first psycho-oncology clinical interest group was formed under the auspices of COSA in 1996 by Stewart Dunn, becoming an incorporated society (OzPos) in 2008. Psychosocial research began in 1986 within the state Cancer Councils' behavioural research units, and has matured with the emergence in 2004 of the Psycho-Oncology Co-operative Research Group (PoCoG), one of the 14 national cancer clinical trial groups funded by Cancer Australia, coming together under the umbrella of COSA.

Consumers have walked hand in hand with Australian cancer researchers to advance the field of psycho-oncology