

Literature review

Consumer engagement in aged care



Australian Government
Aged Care Quality and Safety Commission

Engage
Empower
Safeguard

Contents

Chapter 01 – Context	3
Background	3
Purpose of the literature review	4
Selection of resources	5
Chapter 02 – Key concepts and principles	6
Consumer-centred care	6
Concept	6
Benefits	7
Principles	9
Challenges/barriers to implementation	11
Co-design and consumer engagement	12
Concepts	12
Benefits	14
Principles	17
Challenges	19
Chapter 03 – Strategies and tools for engaging consumers	24
Context	24
Key resources	25
Additional resources	37
Chapter 04 – Summary	60
Key findings	60
Next steps	62
Bibliography	63

Context

01

Background

Over the past ten years there has been significant reform of the aged care sector in Australia, with a greater emphasis on empowering consumers to play an active role in determining their own needs and directing their care. With the introduction of the new Aged Care Quality Standards from 1 July 2019, it is more important than ever that the experience of aged care consumers is put at the centre of planning, delivering and reviewing care.

As part of its responsibilities for protecting and enhancing the safety, health, well-being and quality of life of aged care consumers, the Aged Care Quality and Safety Commission (the Commission) has identified and developed a range of best practice strategies and tools for providers of aged care to engage with consumers and their representatives.

To inform this piece of work, we have undertaken a literature review of co-design and consumer engagement to:

- understand how co-design has been successfully applied in different sectors both in Australia and internationally, which could be applied in the Australian aged care sector
- explore how co-design and consumer engagement are tailored for different purposes and to include consumers from diverse backgrounds
- document existing successful practices of co-design and consumer engagement in aged care services, to support the delivery of consumer directed care
- identify better practice strategies and tools for engaging with consumers and consider how these may be adapted to suit the Australian aged care context and be applied across different care settings on an ongoing basis.

Purpose of the literature review

This literature review examines published peer-reviewed articles and a broader set of literature, including strategies, reports, guidelines and toolkits to gain an understanding of existing models of co-design that have been successfully applied in a range of sectors both in Australia and internationally, which could be applied in the Australian aged care sector.

Sources identified in the literature review cover:

- a number of different settings and sub-settings, including health, disability, community, aged care and business
 - We are mindful that different consumer engagement strategies work very differently in different environments (e.g. in different countries or against different expectations). As such, we will provide the context for the approaches described as part of the literature review.
 - We will also identify approaches that may be applicable to different types of aged care. For example, engagement in the context of short-term care, such as respite, would be different to engagement where a longer relationship is anticipated such as in permanent residential care.

- engagement with a diverse range of consumers, including consumers from different backgrounds and with different needs (e.g. consumers with a cognitive impairment, consumers who experience challenges communicating, consumers who are Indigenous, from culturally and linguistically diverse backgrounds, or lesbian, gay bi-sexual, transgender and/or intersex (LGBTI) consumers)
- all aspects of engagement (including informing, consulting, empowering, involving and collaborating).

This literature review focuses on the inter-related concepts of consumer-centred care, co-design and consumer engagement. We are mindful that people import different meanings to these terms and there are no universal definitions; some people prefer different terminology such as co-production and consumer empowerment.

The literature review is broken into two parts:

- **Chapter 2** distils the key concepts and principles from the range of resources reviewed.
- **Chapter 3** summarises each of the better practice resources we have identified and discusses how these may inform the literature review.

Selection of resources

Key phrases and terms that have been applied in the review of literature on Google Scholar and Pub Med Central have included:

- co-design in aged care
- co-design best practice models
- person-centred care in aged care
- co-production in aged care
- consumer engagement
- shared decision making.

There is a significant volume of information returned by these search terms, particularly when taking into account ideas and best practice models outside the aged care sector (particularly in health care settings). In selecting resources for review, articles were examined for their relevance and applicability in the aged care context in order to narrow the scope of information.

The review also included toolkits, guidance materials, policy statements, frameworks and reports produced by government and non-government agencies.

Key concepts and principles

Consumer-centred care

Concept

Consumer-centred care is broadly described in the literature as care and services that are designed around the consumer and delivered in a way that meets the individual's goals, needs and preferences. Consumer-centred care sees the consumer as an equal partner in planning, developing and monitoring care.

Different terms are used throughout the literature, including 'person-centred care', 'patient-centred care' and 'personalised care' (with no globally accepted definition). However, a consistent theme across the literature is that this type of care is provided in a way that is respectful of, and responsive to, the preferences, needs and values of patients and consumers.¹ For the purposes of this literature review, the term 'consumer-centred care' is used to refer to this type of care, although direct quotes from the literature may use alternative terms.

A number of sources note that consumer-centred care is not just about giving people what they want, or about particular activities, but about sharing decisions, finding out what is important to people and making changes to improve a person's experience of care and help them to be more independent. Consumer-centred care is as much about the way we think about care and relationships as the actual services available.

02

¹ Australian Commission on Safety and Quality in Health Care, Patient-Centred Care: Improving Quality and Safety by Focusing Care on Patients and Consumers – Discussion Paper, September 2010.

Benefits

The concept of consumer-centred care has gained increasing prominence, as organisations seek to partner with consumers to deliver outcomes across a broad range of sector and programs. Service providers are looking for ways to involve consumers in all aspects of their service, including in service design, planning, delivery, monitoring and evaluation.

The World Health Organization and United Nations Children's Fund (UNICEF) Declaration of AlmaAta states:

'The people have the right and duty to participate individually and collectively in the planning and implementation of their health care'.²

The Aged Care Quality Standards focus on quality outcomes for consumers, shifting away from a focus on provider processes.³ Strong consumer engagement is a foundation of the new Standards, with providers required to demonstrate how consumers are involved in the planning, delivery and review of their care and services.

Making sure that people are involved in (and central to) their care is now recognised as a key component of delivering high quality health care. Engaging patients is integral to improving the quality, responsiveness, safety and accountability of services, and directly supports health and well-being outcomes.

2 World Health Organization and UNICEF, September 1978, *Declaration of Alma-Ata*. International Conference on Primary Health Care, Alma-Ata USSR.

3 Australian Government Department of Health, February 2019, *Single set of quality standards, the Aged Care Quality Standards*.

Putting consumers at the centre of their care can:

- improve the quality of the services available and the consumer's experience of care
- improve consumer outcomes and satisfaction with care and services
- encourage consumers to be accountable for their health and well-being and become more active in looking after themselves
- encourage consumers to be more involved in decisions about their care so they get services and support that are appropriate for their needs
- help staff to provide better tailored care and services for consumers with diverse needs
- improve professional satisfaction and confidence in the care provided
- reduce pressure on health and social services.⁴

Research also describes that when consumers are effectively engaged in their care, service providers and care staff also benefit from increased knowledge and empowerment, consumer loyalty and accountability, increased mutual respect and enhanced relationships, and flexibility and innovation in care delivery.⁵

'Developing and fostering strong consumer relationships is fundamental to achieving best outcomes in care and also financial sustainability.'⁶

A number of studies have explored the benefits of consumer-centred care. While quantitative evidence to support these benefits may be limited, it is widely recognised that when successfully implemented, consumer-centred care improves outcomes for all involved (including consumers, their friends, families and carers, service providers and those involved in delivering the care).

Noting the challenges in measuring outcomes, much of the evidence relies on consumer satisfaction and the feedback of those involved in delivering care.

Evidence on the financial benefits of consumer-centred care is limited.

4 Health Innovation Network South London, *What is person-centred care and why is it important?*

5 COTA Australia, September 2014, *The voice of consumers in home care: a practical guide.*

6 COTA Australia, September 2014, *The voice of consumers in home care: a practical guide.*

Principles

The principles for successfully implementing a consumer-centred approach to care are well documented in the literature and are outlined briefly below.

Effective leadership and willingness to embrace change in practice and attitudes

- The literature suggests that moving to a more consumer-centred approach in the Australian aged care sector requires a cultural change from the top down, starting with senior management.⁷
- Effective leadership includes ‘unity of vision, purpose and practice and an empowering and distributed leadership’.⁸
- Managerial leadership affirming the benefits of consumer-centred care is fundamental to empowering staff to make change and ensuring the sustainability of consumer-centred care practices.^{9,10}
- The focus on consumers must be incorporated into the organisational framework (such as the legislation and standards) underpinning expectations of service providers.¹¹
- A consumer-centred organisational culture should embrace risk and support staff to be flexible and try new things to develop innovative and collaborative solutions to improve consumer outcomes.

Education and training to promote learning and skills development for care staff and understanding and autonomy for consumers

- Education and training must be at the forefront of changing the culture in aged care and needs to be done on a continuous basis.¹²
- Including the principles of consumer-centred care in education and training for managers and staff contributes to their understanding of and commitment to providing consumer-centred care (including consistent and sustained recognition and maintenance of the consumer’s autonomy).^{13,14}
- It is also important to educate consumers and their representatives to support informed decision-making and self-determination. The literature consistently identifies that access to information (in a format that is meaningful to the consumer) is fundamental to support maintained dignity and independence.^{15,16}

7 Royal Commission into the Aged Care Quality and Safety Commission, May 2019, Statement of Professor Henry Brodaty, p.1912.

8 Centre for Policy on Ageing, September 2012, *How can the care experience of older people in care homes be improved: findings from five PANICOA studies*, [available at www.panicoa.org.uk/studies]

9 Santana M J, et. al., 2018, How to practice person-centred care: A conceptual framework, *Health Expect.*, vol 21, no. 2, pp. 429-440.

10 Grant-Nierman M, May 2016, *Partnering with Patients to Improve Quality, Safety and the Patient Experience*, Agency for Healthcare Research and Quality.

11 Lindeman M A, et. al., 2003, Changing Practice in Residential Aged Care Using Participatory Methods, *Education for Health*, vol. 16, no. 1, pp. 22-31.

12 Royal Commission into the Aged Care Quality and Safety Commission, May 2019, Statement of Professor Henry Brodaty, p.1912.

13 Kim S K, Park M, 2017, Effectiveness of person-centred care on people with dementia: a systemic review and meta-analysis, *Clinical Interventions in Ageing*, vol. 12, pp. 381-397

Empowering staff at all levels to make change

- Using a process that encourages staff involvement in identification of issues and actions can facilitate change in the practice of care.
- Involving all staff in generating suggestions and solutions to improve practice (regardless of their rank or area of expertise) encourages work practices that are inclusive and empowering of all staff.¹⁷

Ongoing communication and information sharing

- Continual information sharing and integrated communication between all people involved in a person's care, consumers and their representatives are vital for consumer-centred care.¹⁸
- Building rapport and trust among stakeholders is essential to encourage participation and engagement in the service.¹⁹
- Active coordination among all healthcare and supportive service providers ensures more connected, integrated and holistic care.²⁰
- Ongoing engagement and discussion with the consumer is necessary to understanding the effectiveness of care and services, including how these meet the consumer's needs and impact on their quality of life.²¹ Understanding the consumer's motivations, priorities and preferences and what they want to achieve also helps to provide a specific, measurable and realistic goal.
- Communication also includes creating an environment where consumers feel safe and free to speak out or voice their concerns.²²

14 Goodwin C, 2016, Person-Centered Care: A Definition and Essential Elements, *Journal of the American Geriatrics Society*, vol 64, pp. 15-18.

15 Gill L, Bradley S L, Cameron I D, Ratcliffe J, 2018, How do clients in Australia experience Consumer Directed Care? *BMC Geriatrics*, vol. 18, no. 148.

16 Alfred Health, *Improving lives Quality Account 2015-16*.

17 Lindeman M A, et. al. 2003, Changing Practice in Residential Aged Care Using Participatory Methods, *Education for Health*, vol. 16, no. 1, pp. 22-31.

18 Goodwin C, 2016, Person-Centered Care: A Definition and Essential Elements, *Journal of the American Geriatrics Society*, vol 64, pp. 15-18.

19 COTA Australia, September 2014, *The voice of consumers in home care: a practical guide*.

20 Health Innovation Network South London, *What is person-centred care and why is it important?*

21 Gill L, Bradley S L, Cameron I D, Ratcliffe J, 2018, How do clients in Australia experience Consumer Directed Care? *BMC Geriatrics*, vol. 18, no. 148.

22 Centre for Policy on Ageing, September 2012, *How can the care experience of older people in care homes be improved: findings from five PANICOA studies*, [available at www.panicoa.org.uk/studies]

Measuring and monitoring performance and continuous improvement

- Performance measurement and quality improvement must be focused on using feedback from consumers, their representatives and the people involved in their care to continuously improve the care and services provided.²³
- Consumer feedback and outcome data should be embedded into the organisation's governance and input into the design of services.²⁴
- 'Organisations practicing person-centred care should use measurement tools that focus on consumer and caregiver satisfaction. Other measures of person-centred care could include integration and communication of health and long-term services and supports; system-level measurement of outcomes (e.g. avoidable hospital admissions), structures (e.g. organisational culture) and processes (e.g. individualised care planning); and individual level outcomes, which could include mental health outcomes, caregiver stress and strain, patient satisfaction with role in decision-making and shaping care, alignment of goals with the care received, and goal attainment scaling.'²⁵

Challenges/barriers to implementation

A number of authors note that for many years, healthcare providers have been encouraged to partner with patients to deliver personalised care and although there are numerous conceptual frameworks in the literature for consumer-centred care, practical guidance that assists with implementation is limited.

Statements to the Royal Commission into Aged Care Quality and Safety have reiterated this point in the context of aged care, noting that while consumer-centred care has been associated with high quality care in Australia and abroad over the past two decades, there are still many residential care services that claim to provide it, but 'their actions do not always match the rhetoric. Task orientated rather than person orientated approaches continue to prevail.'²⁶

For many organisations, successful implementation of the principles outlined above require large-scale structural, governance and cultural changes. A key focus of this project will be providing simple strategies and tools for aged care providers to use such that they can incrementally shift towards a fully consumer-centred care approach.

Challenges to implementation of consumer-centred care in the aged care sector will be further explored through consultation with aged care providers, including to explore solutions and the development of tools to help overcome barriers.

23 Royal Commission into the Aged Care Quality and Safety Commission, May 2019, Statement of Professor Henry Brodaty, p.1912.

24 KPMG Global Healthcare, 2014, *Creating new value with patients, carers and communities*.

25 Goodwin C, 2016, Person-Centered Care: A Definition and Essential Elements, *Journal of the American Geriatrics Society*, vol 64, pp. 15-18.

26 Royal Commission into the Aged Care Quality and Safety Commission, May 2019, Statement of Professor Henry Brodaty.

Co-design and consumer engagement

Concepts

Co-design and consumer engagement are essential foundation stones for consumer-centred care and while these are two distinct concepts, the principles are generally consistent.

Co-design

Co-design means involving all stakeholders (consumers, their families and carers, and staff) in the design of care and services to ensure they achieve the desired outcomes for consumers and that consumer experiences are used to drive improvements.

Co-design involves stakeholders reflecting on their experiences of a service to identify improvement priorities and devise changes.²⁷

The literature often distinguishes between co-design and similar concepts such as co-production or co-creation. These concepts refer to the collective engagement of stakeholders in any creative activity.^{28, 29}

While the term co-design, in a narrower sense, refers to the involvement of stakeholders across the entire design process. For the purposes of the literature review, the term co-design has been used to describe the concept of involving people in the production of their services. This includes the processes and activities that bring together different perspectives on a common issue to create a shared agenda to achieve change.^{30, 31}

During co-design, active collaboration occurs between all participants, with service users regarded as ‘experts of their experiences’.³² Co-design involves more than participants saying what they want from interventions or services; it involves jointly exploring and articulating needs and behaviours and developing solutions.³³

The literature notes that the term co-design is sometimes incorrectly applied to processes that would be more correctly identified as ‘consultation’ or ‘engagement’ where users’ views on a need, idea, or product are sought, often in a more limited manner.

27 Bown, H (2013) *Co-production involving and led by older people: An Evidence and Practice Review*, National Development Team for inclusion, <http://otbs.org/wisdom/>

28 Thabrew H, Fleming T, Hetrick S and Merry S 2018 ‘Co-design of eHealth Interventions With Children and Young People’ *Front. Psychiatry*, vol. 9, p. 481.

29 Sanders EBN, Stappers PJ., 2008, ‘Co-creation and the new landscapes of design’ *CoDesign*, vol. 4, pp. 5–18.

30 Buffel, T, 2018, ‘Social research and co-production with older people: Developing age-friendly communities’, *Journal of Aging Studies*, 44, pp.52-60

31 Brown, H, 2013, *Co-production involving and led by older people: An Evidence and Practice Review*, National Development Team for inclusion.

32 Sleeswijk Visser F, Stappers PJ, Van der Lugt R, Sanders EBN, 2005, ‘Context mapping: experiences from practice’ *CoDesign*, vol. 1, pp. 119–49.

33 Sanders EBN, 2002, ‘From user-centred to participatory design approaches’, *Design and the Social Sciences: Making Connections*, London, Taylor and Francis, pp. 1–8.

Consumer engagement

Consumer engagement is about involving consumers (and their families and carers) in all aspects of care. This means engaging consumers in discussions and decisions about their day-to-day care as well as engaging them in service planning and delivery, setting priorities and identifying improvements to care and services, and measuring and evaluating health care services. Consumer engagement can occur in many ways at different levels – through informing, consulting, involving, collaborating or empowering, depending on the circumstances.

The five levels of engagement are based on the International Association for Public Participation, IAP2 Spectrum:³⁴

- **inform** – to provide consumers with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions
- **consult** – to obtain feedback on analysis, alternatives and/or decisions
- **involve** – to work directly with consumers throughout the process to ensure their concerns and aspirations are consistently understood and considered
- **collaborate** – to partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution
- **empower** – to place final decision-making in the hands of the public.

The Spectrum shows that differing levels of engagement are legitimate depending on the goals, timeframes, resources and levels of concern in the decision to be made.

34 International Association for Public Participation, 2014, *IAP2 Spectrum*.

Benefits

While the principles of co-design and consumer engagement are well documented, the evidence for these directly improving consumer outcomes is less so. However, there is a raft of literature discussing the various benefits of co-design and consumer engagement (particularly in the context of health services) for the consumers themselves, as well as for their families, carers and communities, service providers and staff.

Improved consumer outcomes

- A number of studies have demonstrated that the engagement of consumers in the activities of an organisation (including in policy, planning, service delivery, research and evaluation) can play a significant role in improving quality service outcomes, including by creating services that better tailored to meet individual needs and preferences and are more likely to meet the particular needs of more vulnerable groups.³⁵
- Some evidence from the health sector suggests that involving consumers leads to improved health outcomes, a more trusted health system and a more satisfied workforce. Where consumers are viewed as equal and important members of health services, research groups and policy development, there are generally improved outcomes and experiences for consumers. In addition, meaningful consumer engagement can build a trusted and confident health service.³⁶
- Engagement of consumers can support service providers and staff to identify consumer priorities and gaps in services and training. Consumer perspectives can assist in making health information and services more balanced and relevant to consumers and increase the chance of these meeting the needs of consumers.³⁷
- Engaging stakeholders in the context of an individual's health care can provide access to a more diverse range of skills and knowledge, resulting in improved integration of services and more innovative care solutions.³⁸
- In the context of dementia, co-designed activities and interventions can help people to build their self-esteem, identity and dignity, help to keep them connected to their community, and in some circumstances, can delay the need for formal support and avoid the need for crisis responses.³⁹
- Reduced readmission and length of stay⁴⁰ (including because patients are empowered to more actively manage their own health) although substantive evidence in this area is limited.

35 Foroushani, S, Travaglia, J, Eikli, M and Braithwaite, J, 2012, *Consumer and community engagement: A review of the literature*, Australian Institute of Health Innovation, Agency for Clinical Innovation and University of NSW, Sydney, p.39

36 Cancer Australia and Cancer Voices Australia, 2011. National Framework for Consumer Involvement in Cancer Control. Cancer Australia, Canberra, ACT.

37 NHMRC 2006, *Guide to effective participation of consumers and communities in developing and disseminating health information*, Canberra, Australian Government.

38 Quality Improvement and Change Management Unit, 2017, *You Matter: A Guideline to support engagement with consumers, carers, communities and clinicians in health*. Perth, Western Australian Department of Health.

39 Rodgers, P, 2016, 'Co-designing with people living with dementia', *International Journal of CoCreation in Design and the Arts*, Vol 14, Issue 3, pp.188-202

40 Kennedy A, Reeves D, Bower P, et al, 2007, 'The effectiveness and cost effectiveness of a national lay-led self care support programme for patients with long-term conditions: a pragmatic randomised controlled trial', *Journal of Epidemiology & Community Health*, vol. 61, pp. 254-261.

Increased consumer autonomy and ownership

- Actively involving consumers in their health care increases their control over their health status, including through improved health literacy and understanding of the systems and services and how these impact on their health. This can result in improved consumer autonomy and ownership of service design, delivery and evaluation.⁴¹
- At an individual level, consumers involved in engagement activities have reported that such involvement made them feel as though they were being listened to by professionals, that their ideas were being acted upon, and that their experience as a patient was being used to help others.^{42,43}
- Building effective consumer networks can contribute to improvements in the wider community and in the active citizenship of individuals and groups.⁴⁴

Enhanced credibility, transparency and applicability of services and programs

- Engaging consumers is considered key to establish credibility, improve relevance and gain consumer buy-in.⁴⁵ When stakeholders are engaged early in a process, they are more likely to understand the process and feel that their insights are incorporated. Consumers have reported that it gave them a sense of investment in the process and findings, as opposed to feeling that changes were simply 'announced' to them or imposed on them at the end.⁴⁶
- Stakeholders feeling that they have been meaningfully engaged in a process can lead to improved uptake of changes, as it is more likely the changes are relevant to real life situations faced by consumers, their families and staff. Stakeholders are also more likely to become advocates for the changes thereby facilitating more widespread dissemination and uptake.^{47,48}

41 Government of South Australia, SA Health, 2015, *Guide for Engaging with Consumers and the Community*.

42 Fudge, N., Wolfe, C. D. A. & McKeivitt, C. 2011, 'Assessing the promise of user involvement in health service development: ethnographic study', *BMJ*, online.

43 Crawford, M. J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N. & Tyrer, P. 2002 'Systematic review of involving patients in the planning and development of health care' *BMJ*, vol. 325, p. 1263.

44 Krebs, V. & Holley, J. 2006, 'Building smart communities through network weaving', *Appalachian Center for Economic Networks*.

45 Buckland D, Bashir N, Moore JE, Straus S, et al. 2017, *Canadian Task Force on Preventive Health Care patient engagement protocol*. Toronto: Li Ka Shing Institute, St. Michael's Hospital.

46 Agency for Healthcare Research and Quality, March 2014, *Research White Paper: Defining the Benefits of Stakeholder Engagement in Systematic Reviews*, AHRQ Publication No. 14-EHC006-EF, U.S. Department of Health and Human Services

47 Alam, I. 2002, 'An exploratory investigation of user involvement in new service development' *Journal of the Academy of Marketing Science*, vol. 30, no. 3, pp. 250-261.

48 Steen, M, Manschot, M and De Koning, N 2011 'Benefits of Co-design in Service Design Projects', *International Journal of Design*, vol.5, no.2, pp.53-59

- Engaging with the individuals, groups of individuals or organisations that are affected by or can affect an organisation's activities and responding to their concerns makes organisations perform better. It increases their knowledge and contributes to their license to operate.⁴⁹
- Some studies show that consumer engagement can also increase their understanding of and trust in the staff and services being delivered. This in turn, can lead to improved resolution of conflict and complaints and improved staff satisfaction and retention.⁵⁰

'Effective stakeholder engagement is increasingly contributing to organisational resilience and flexibility, to learning and innovation, to the identification of new opportunities, and ultimately to the improvement of sustainable performance.'⁵¹

Some studies cite increased efficiency and reduced costs as likely benefits of engaging consumers in the delivery of their services⁵², although this is debated in the literature, with other studies citing the cost of engaging consumers as a barrier.^{53, 54, 55}

49 AccountAbility, 2005, AA1000SE *Stakeholder Engagement Standard*.

50 Quality Improvement and Change Management Unit, 2017, *You Matter: A Guideline to support engagement with consumers, carers, communities and clinicians in health*. Perth, Western Australian Department of Health.

51 Australian Government Department of Health, *Stakeholder Engagement Framework*.

52 Quality Improvement and Change Management Unit, 2017, *You Matter: A Guideline to support engagement with consumers, carers, communities and clinicians in health*. Perth, Western Australian Department of Health.

53 Ennis, L., Rose, D., Callard, F., Denis, M. & Wykes, T. 2011. Rapid progress or lengthy process? electronic personal health records in mental health. *BMC Psychiatry*, 11.

54 Doughty, C. & Tse, S. 2011 'Can consumer-led mental health services be equally effective? An integrative review of CLMH services in high-income countries' *Community mental health journal*, vol. 47, pp. 252-66.

55 Dubois, J. M., Bailey-Burch, B., Bustillos, D., Campbell, J., Cottler, L., Fisher, C. B., Hadley, W. B., Hoop, J. G., Roberts, L., Salter, E. K., Sieber, J. E. & Stevenson, R. D. 2011 'Ethical issues in mental health research: the case for community engagement', *Curr Opin Psychiatry*, vol. 24, pp. 208-14.

Principles

Key principles associated with putting co-design and consumer engagement into practice include:

Working together from the beginning to identify the issues and goals

- Co-design and consumer engagement bring different stakeholders together (staff at all levels and all kinds of organisations and sectors, with the people and communities who the services are for).
- All participants should be engaged early to help define the problem, create shared goals and develop processes for working together collaboratively.⁵⁶
- A genuine, ongoing partnership between service users and providers is a crucial element to effective co-design.⁵⁷ Consumers, families and staff work together from the beginning with an equal voice and a sense of ownership and control.

Partnership

- Co-design is collaborative, promoting an equitable partnership between stakeholders. This is often described as requiring a shift in the power balance between professionals and consumers.⁵⁸
- In co-design, consumers, families and staff work together from the beginning with an equal voice and shared ownership and control.⁵⁹
- Consumers are considered active partners driving change and the importance of consumer contribution is recognised throughout the process.⁶⁰
- The concept of shared decision making is an underlying principle of consumer engagement and speaks to the re-distribution of power between clinicians/providers and consumers.⁶¹

56 Steen, M., Manschot, M., & De Koning, N. 2011 'Benefits of co-design in service design projects. *International Journal of Design*, vol. 5, no. 2, pp. 53-60.

57 Bown H and Raines T, 2013, Co-production involving and led by older people: An Evidence and Practice Review, *National Development Team for Inclusion*, www.ndti.org.uk.

58 Carrie Hayter Consulting, 2016, *Nothing about us without us – older citizens co-producing residential services – six key steps*, July 2016.

59 Agency for Clinical Innovation, Experience-based co-design approach, www.aci.health.nsw.gov.au.

60 NSW Agency for Clinical Innovation, Consumer engagement – giving a voice to key stakeholder perspectives.

61 Foroushani, S, Travaglia, J, Eikli, M and Braithwaite, J, 2012, *Consumer and community engagement: A review of the literature*, Australian Institute of Health Innovation, Agency for Clinical Innovation and University of NSW, Sydney, p.39.

Openness and transparency

- Clear and transparent processes (e.g. administrative, feedback, change, reporting, communication) are fundamental to effective co-design.⁶² Limitations and non-negotiables must be communicated up front such that each individual is fully aware of the level of influence they have in the process.
- The decision-making points and the process for reaching a decision are made clear to all participants.⁶³
- The role and expectations of consumers (including in seeking feedback from and communicating with those outside of the process) must also be made clear.⁶⁴

Empower participants to contribute

- Co-design is inclusive, supporting the involvement of all stakeholders. It works best when everyone commits to contributing and benefits from being involved.⁶⁵
- In order to elicit maximum engagement from all participants, people need to feel there is a safe space to speak up and be listened to.⁶⁶
- Consumers need to be empowered to participate in the process. This could include by providing training or briefing for consumers on the expectations of their role, providing relevant background information, actively seeking consumer input, providing a safe space to share views and concerns, accommodating different needs, communicating through a range of mechanisms, etc.⁶⁷
- Specific efforts must be made to access and engage more vulnerable individuals and marginalised communities.⁶⁸
- Co-design initiatives often involve skill development and capability building for all participants. Participants can all learn from each other.⁶⁹

62 NSW Agency for Clinical Innovation, Consumer engagement – giving a voice to key stakeholder perspectives

63 Community West Inc, *Co-producing Aged Care Services with a Wellness Focus, [Part One: A Guide and Part Two: A Toolkit, Part Three: Tools & Activities]*, Step Forward – Together project funded by the Australian Government, September 2016.

64 Steen, M, Manschot, M and De Koning, N, 2011, 'Benefits of Co-design in Service Design Projects', *International Journal of Design*, Vol.5, No.2, pp.53-59.

65 Community West Inc, *Co-producing Aged Care Services with a Wellness Focus, [Part One: A Guide and Part Two: A Toolkit, Part Three: Tools & Activities]*, Step Forward – Together project funded by the Australian Government, September 2016

66 Elwyn G, Frosch, D and Kobrin S, 2016, Implementing shared decision-making: consider all the consequences, *Implementation Science*, 11: 114

67 NSW Agency for Clinical Innovation, Consumer engagement – giving a voice to key stakeholder perspectives

68 Buffel, T, 2018, 'Social research and co-production with older people: Developing age-friendly communities', *Journal of Aging Studies*, 44, pp.52-60

69 Australian Healthcare and Hospitals Association (AHHA) and Consumers Health Forum of Australia (CHF), *Experience Based Co-design: a toolkit for Australia*, 2017

Valuing diversity and consumer experience

- The views, experiences and diversity of consumers, families and staff must be acknowledged and valued. Co-design puts an emphasis on gathering real stories from people to understand their experiences of what is going well and what would be better.⁷⁰
- People are seen as assets; with the skills and experiences they bring to the process used to drive change and innovation.⁷¹
- Including a diverse range of participants in the design of improvements provides an opportunity to explore, experiment and innovate with alternative solutions.⁷²

Challenges

While co-design and consumer engagement are more commonly becoming a focus in social interventions, the extent to which consumers are genuinely engaged in shaping an intervention is variable. Co-design can sometimes be used as a buzz word, without directly contributing to service design.⁷³

There are challenges in how to gather and synthesise consumers' views and there is natural variation in the views of different consumers.⁷⁴ As such, navigating the decision-making process can be challenging, particularly in ensuring consumers are fully aware of the options and the risks and benefits, and are able to make fully informed decisions.^{75, 76}

While the principles of consumer engagement are broadly accepted, some authors suggest that the evidence for it actually improving patient outcomes is relatively weak. There is debate about the degree to which consumers seek involvement, the best way to involve them and the impact or evidence of the benefit of consumer involvement.^{77, 78} It is difficult to determine the impact of specific interventions and strategies and a strategy that has been successful in one context may fail in another.

70 Moyez Jiwa (ed) (2018) Patients as co-designers to improve the quality of care, *The Journal of Health Design*, Vol 3, No 1.

71 Sanders, E 'From User-Centred to Participatory Design Approaches', 2002 in Frascara, J (ed) *Design and the social science: Making connections*, pp.1-8, London, Taylor and Francis

72 Australian Healthcare and Hospitals Association (AHHA) and Consumers Health Forum of Australia (CHF), *Experience Based Co-design: a toolkit for Australia*, 2017

73 Steen, M., Manschot, M., & De Koning, N. 2011 'Benefits of co-design in service design projects', *International Journal of Design*, vol. 5, no. 2, pp. 53-60.

74 Menon D, Stafinski T, 2011 'Role of patient and public participation in health technology assessment and coverage decisions', *Expert Rev Pharmacoecon Outcomes Res.*, vol. 11, no. 1, pp. 75-89.

75 O'Connor, A., Stacey, D., Bennett, C. L., Barry, M. J., Col, N. F., Eden, K. B., Holmesrovner, M., Llewellynthomas, H., Lyddiatt, A., Legare, F. & Thomson, R. 2011. Decision aids for people facing health treatment or screening decisions [Systematic Review]. *Cochrane Database of Systematic Reviews*, vol. 10, no. 10.

76 Curtis, L. C., Wells, S. M., Penney, D. J., Ghose, S. S., Mistler, L. A., Mahone, I. H., Delphin-Rittmon, M., Del Vecchio, P. & Lesko, S. 2010 'Pushing the envelope: shared decision making in mental health', *Psychiatric rehabilitation journal*, vol. 34, pp. 14-22.

77 Foroushani, S, Travaglia, J, Eikli, M and Braithwaite, J, 2012, *Consumer and community engagement: A review of the literature*, Australian Institute of Health Innovation, Agency for Clinical Innovation and University of NSW, Sydney, p.39

78 Helping Hand, Consumer and Engagement Framework, <http://www.helpinghand.org.au/wp-content/uploads/2015/04/CCEFramework.pdf>

As noted in a literature review of consumer and community engagement published by the University of NSW:

‘The principle of consumer and community engagement has been acknowledged and applied in healthcare for decades. Despite this long-standing commitment and the plethora of approaches, strategies, techniques and tools employed, the evidence base for this field remains diffuse and hard to synthesise. Available evidence primarily supports local, context-specific interventions.

It is difficult to extrapolate a clear model for engagement which is evidence-based. Rather, what emerges from the evidence is an eight-stage model for consumer and community engagement incorporating key elements which underpin the principles, the processes and the practices of consumer and community engagement. It is clear that attempts at engagement at each level of the health system, micro, meso and macro, need to take these elements into account to plan, execute, and evaluate consumer and community engagement activities accordingly.’⁷⁹

Other reported challenges in engaging consumers effectively in co-design include:

Resourcing

- Facilitating consumer engagement in their health care can impose a financial burden and can be perceived as taking resources away from the actual provision of care.^{80,81,82}
- Consumer engagement takes staff time and needs to be identified as a priority for the organisation. Adding a complex consumer participation and engagement agenda to an already heavy workload without creating the time and committing resources to do it well can limit its effectiveness.⁸³
- Building the right mindset to embrace co-design (balancing workload with engagement and quality improvement) takes time and energy for staff and consumers. If there is limited support for ongoing engagement with consumers, the co-design process may be undermined.
- The literature discusses the need for financial and other incentives to promote shared decision making.⁸⁴

79 Foroughani, S, Travaglia, J, Eikli, M and Braithwaite, J 2012 ‘Consumer and community engagement: A review of the literature’, *Australian Institute of Health Innovation, Agency for Clinical Innovation and University of NSW, Sydney*, p. 63.

80 Ennis, L., Rose, D., Callard, F., Denis, M. & Wykes, T. 2011. Rapid progress or lengthy process? electronic personal health records in mental health. *BMC Psychiatry*, 11.

81 Doughty, C. & Tse, S. 2011 ‘Can consumer-led mental health services be equally effective? An integrative review of CLMH services in high-income countries’ *Community mental health journal*, vol. 47, pp. 252-66.

82 Dubois, J. M., Bailey-Burch, B., Bustillos, D., Campbell, J., Cottler, L., Fisher, C. B., Hadley, W. B., Hoop, J. G., Roberts, L., Salter, E. K., Sieber, J. E. & Stevenson, R. D. 2011 ‘Ethical issues in mental health research: the case for community engagement’, *Curr Opin Psychiatry*, vol. 24, pp. 208-14.

83 COTA Australia, September 2014, *The voice of consumers in home care: a practical guide*.

84 Coulter, A., Edwards, A., Elwyn, G. & Thomson, R. 2011 ‘Implementing shared decision making in the UK’, *Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen*, vol. 105, no. 4, pp. 300-304.

Lack of skills and confidence

- Service providers, staff and consumers require the skills and confidence to participate meaningfully in co-design and engagement.
- Many co-design techniques and tools assume particular skills, expertise and processes that rely on the communication, cognitive and creative skills of the participants.⁸⁵ As such, many well-established co-design tools and techniques may not be appropriate in the context of aged care and will require adjustment.
- Consumer literacy in the context of health is an additional challenge to co-design.⁸⁶
- Further, in some engagement processes: input is taken from representative organisations rather than individual consumers; consumers are not aware of the possibility of providing input; the impact or role of consumers may be limited; and although consumers may be represented on committees, they may not be actively involved in decision-making.⁸⁷
- The literature commonly advises training and education of both health professionals and consumers to support effective engagement^{88,89,90}. However, this is not on its own sufficient to ensure the effective implementation of consumer and community engagement strategies.

85 Rodgers, P, 2016, Co-designing with people living with dementia, *International Journal of CoCreation in Design and the Arts*, Vol 14, Issue 3, pp.188-202

86 NHMRC 2006, *Guide to effective participation of consumers and communities in developing and disseminating health information*, Canberra, Australian Government.

87 Menon, D. & Stafinski, T. 2011 'Role of patient and public participation in health technology assessment and coverage decisions' *Expert Review of Pharmacoeconomics & Outcomes Research*, vol. 11, pp. 75-89.

88 Foroushani, S, Travaglia, J, Eikli, M and Braithwaite, J 2012 'Consumer and community engagement: A review of the literature', *Australian Institute of Health Innovation, Agency for Clinical Innovation and University of NSW, Sydney*, p. 63.

89 Legare, F., Ratté, S., Stacey, D., Kryworuchko, J., Gravel, K., Graham, I. D. & Turcotte, S. 2011 'Interventions for improving the adoption of shared decision making by healthcare professionals [Systematic Review]'. *Cochrane Database of Systematic Reviews*.

90 Lyttle, D. J. & Ryan, A. 2010, 'Factors influencing older patients' participation in care: a review of the literature' *International journal of older people nursing*, vol. 5, pp. 274-82.

Disruption to traditional power relations

- Organisational, cultural and contextual factors affect the integration of consumer and community engagement approaches in healthcare services. These can impact on staff and consumer roles, identity and expectations. Implementing shared decision making by changing long-established communication styles has proven a challenge even for educated and motivated professionals.^{91,92,93}
- Power relationships are often deeply ingrained and the transition to sharing control can present a challenge for staff.^{94,95}

Engagement with vulnerable groups

- People's preference for involvement in decision making can vary based on characteristics such as age, educational level, disabilities and ethnic and cultural backgrounds.⁹⁶
- The National Health and Medical Research Council (NHMRC) emphasises the need for the utilisation of multiple engagement strategies and approaches to ensure diversity of consumer perspectives, particularly for minority and vulnerable groups.⁹⁷
- Targeted strategies may be required to effectively engage with diverse consumer groups, including for example by:
 - engaging with consumer representatives where appropriate, to provide input on behalf of consumer groups or individual consumers⁹⁸

91 Curtis, L. C., Wells, S. M., Penney, D. J., Ghose, S. S., Mistler, I. A., Mahone, I. H., Delphin-Rittmon, M., Del Vecchio, P. & Lesko, S. 2010. Pushing the envelope: shared decision making in mental health. *Psychiatric rehabilitation journal*, vol. 34, pp. 14-22.

92 Cornuz, J., Kuenzi, B. & Krones, T. 2011. Shared decision-making development in Switzerland: Room for improvement! *Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen*, vol. 105, no. 4, pp. 296-299.

93 Fine, E., Reid, M. C., Shengelia, R. & Adelman, R. D. 2010. Directly observed patient-physician discussions in palliative and end-of-life care: A systematic review of the literature. *Journal of Palliative Medicine*, vol. 13, no. 5, pp. 595-603.

94 Citing learnings and challenges experienced by Cavalry Community Care (NSW) in piloting co-production, in Co producing aged care services with a wellness focus, p .34

95 Dimopoulos-Bick, T, Dawda, P, Maher, L, Verma, R and Palmer, V (2018) Experience based co-design: Tackling common challenges, *The Journal of Health Design*, Vol 3, No 1, p.89

96 Curtis, L. C., Wells, S. M., Penney, D. J., Ghose, S. S., Mistler, I. A., Mahone, I. H., Delphin-Rittmon, M., Del Vecchio, P. & Lesko, S. 2010. Pushing the envelope: shared decision making in mental health. *Psychiatric rehabilitation journal*, vol. 34, pp. 14-22.

97 NHMRC 2006, *Guide to effective participation of consumers and communities in developing and disseminating health information*, Canberra, Australian Government.

98 Australian Healthcare and Hospitals Association (AHHA) and Consumers Health Forum of Australia (CHF), *Experience Based Co-design: a toolkit for Australia*, 2017.

- using language that is accurate, respectful, inclusive, empowering and non-stigmatising and asking questions when engaging with people with dementia^{99, 100}
- understanding cultural sensitivities and differences and responding to these differences in engaging with culturally and linguistically diverse consumers^{101, 102}
- building trust and relationships over a sustained period to develop shared understandings and goals when working with Aboriginal and Torres Strait Islander people^{103, 104}
- using gender-sensitive language that is inclusive and non-discriminatory to engage with LGBTI people.^{105, 106}

Barriers to engaging with consumers in aged care

In aged care, there are additional complexities in using co-design and consumer engagement to deliver consumer-centred care.

Working with consumers to adapt services to meet their individual goals, needs and preferences challenges the historical pillars and institutional structures of Australia's aged care system. According to the literature, many aged care providers continue to question the role of the consumer in quality improvement. Some of the commonly cited additional challenges in engaging with older consumers, include:

- sensory impairment
- cognitive difficulties
- frailty and fatigue
- lack of mobility
- isolation
- lack of technical knowledge
- lack of confidence
- an unwillingness to criticise their service provider (either because of the risk of appearing ungrateful or for fear of services being withdrawn).^{107, 108}

99 Dementia Australia, May 2018, Dementia language guidelines.

100 Alzheimer's Australia Vic and Ethnic Communities Council of Victoria, October 2008, *Perceptions of dementia in ethnic communities*.

101 Diversicare and Ethnic Communities Council of Queensland for the Queensland Government, May 2015, *Little Book of Cultural Tips*.

102 FECCA, *Access and equity to Feedback and Complaints Mechanisms for Multicultural Communities*.

103 Life Without Barriers, *Engaging with Aboriginal and Torres Strait Islander people: The Life Without Barriers Practice Approach*.

104 benevolent society, *Working with older Aboriginal and Torres Strait Islander people: Research to practice briefing 8*

105 Australian Government Department of Health, February 2019, *Actions to support Lesbian, Gay, Bisexual, Trans and Gender Diverse and Intersex Elders: A guide for consumers*.

106 Victorian Department of Health, *Service guideline on gender sensitivity and safety - Literature review*.

107 COTA Australia, September 2014, *The voice of consumers in home care: a practical guide*.

108 Wherton, J, Sugarhood, P, Procter, R, Hinder, S and Greenhalgh, T, 2015, Co-production in practice: how people with assisted living needs can help design and evolve technologies and services, *Implementation Science*, vol. 10, no. 75.

Strategies and tools for engaging consumers

Context

A key focus of this literature review has been to identify promising strategies and tools for co-design and consumer engagement (being applied internationally and in other sectors) such that these can inform new tools to be published by the Commission specifically for aged care providers and consumers.

As detailed below, we have separated the resources into:

- **key resources:** These are the key strategies and tools we consider most valuable for informing the development of new resources to support aged care providers. These include widely used resources, particularly innovative or comprehensive toolkits and those identified by key stakeholders
- **additional resources:** These are resources that have informed this literature review (and our understanding of different models and strategy of consumer engagement) but are less likely to directly inform the development of new resources.

We are mindful that many of the key resources detailed below are from other sectors and international toolkits. This has been the focus of the literature review to date, noting that the surveys and consultation with aged care consumers and providers are likely to reveal more comprehensive information on strategies and toolkits used in the Australian aged care sector.

03

Key resources

General

The International Association for Public Participation Australasia, 2007, *IAP2 Spectrum of Public Participation*.

IAP2 is an international member association which seeks to promote and improve the practice of community and stakeholder engagement. IAP2 has developed tools that are widely used and acknowledged, including the Core Values for Public Participation (for use in the development and implementation of public participation processes); and the IAP2 Public Participation Spectrum (which assists to select the level of participation that defines the public's role in any community engagement program). The IAP2 Spectrum is used in numerous resources guiding stakeholder engagement, including the Australian Government Department of Health's 'Stakeholder Engagement Framework', COTA's 'the Voice of Consumers in Home Care Practical Guide', the WA Department of Health's 'You Matter Guideline' and SA Health's 'Guide for Engaging with Consumers and the Community'.

The Spectrum shows that differing levels of participation (inform, consult, involve, collaborate, empower) are legitimate depending on the goals, time frames, resources and levels of concern in the decision to be made. The Spectrum also sets out the promise being made to the public at each participation level.

Aged care

Brown H, 2013, *Co-production involving and led by older people: An Evidence and Practice Review*, National Development Team for Inclusion.

This review was undertaken by the National Development Team for Inclusion in Scotland and pulls together a range of published and unpublished literature, as well as findings from a workshop hosted by the Wisdom in Practice program¹⁰⁹. The Wisdom in Practice program was developed by a small independent Scottish charity and supports the development of services led by older people. A range of resources regarding co-production with older people are available on their website including hints and tips, discussion papers and reports (tailored to both consumers and providers).

The review examines the evidence, outcomes and key characteristics of effective co-production involving older people. Co-production involving older people is described at every level of decision making and through activities including research, service and strategy development, evaluation, training, personalised support planning and policy implementation. The review provides examples that demonstrate best practice co-production principles, such as bringing different stakeholders together (i.e. staff at all levels and all kinds of organisations and sectors with the people and communities who the services are about) from the beginning of the design process through delivery and evaluation of outcomes. One example looks at involving older people to recruit, train and support older people to work as community leaders to promote healthy, active ageing.

¹⁰⁹ Outside the Box, *Wisdom in Practice*, [available at: <https://otbds.org/projects/wisdom-in-practice/>].

Findings included that face-to-face methods of engagement (such as meetings and workshops) tend to be utilised the most, but social media and networking techniques are under-developed. A useful tool included in this review is the 'Framework for future action: guiding principles and practices for co-production with older people'. The Framework outlines seven principles of co-production with older people and includes a set of corresponding actions for applying the principles to local practice. The principles are centred around increasing the involvement of older people, focusing on issues that are important to them, ensuring that they are listened to and that their skills and experiences are used in the change process.

This review also highlights priorities for developing co-production with older people that provide a possible pathway for further developing and promoting consumer engagement and co-design in the Australian context.

Community West Inc, *Co-producing Aged Care Services with a Wellness Focus, [Part One: A Guide and Part Two: A Toolkit, Part Three: Tools & Activities]*, Step Forward – Together project funded by the Australian Government, September 2016.

Community West Inc. and COTA Australia were funded by the Australian Government Department of Health (2015 to 2017) to support the aged care services sector to incorporate co-production into organisational service design.

This resource is comprehensive (including a guide, a toolkit and tools and activities) to support aged care service providers in Australia to engage with consumers, with an emphasis on working collaboratively to develop solutions to better meet consumer needs. The resource provides a number of relevant case studies where consumer engagement has been successfully applied to develop interventions in aged care services.

One case study describes Uniting AgeWell's co-design of a physical exercise program using a specialised seniors' gym (HUR gym). Physiotherapists involved consumers in co-designing their own exercise program and a peer buddy system was established so consumers could exercise with and encourage each other. This also promoted social and community connections, which consumers reported as a benefit and motivator for exercising. Uniting AgeWell's HUR gym membership increased from 70 clients in June 2015 to 200 clients in May 2016. The relevant principles that can be drawn from this example are that: it recognised consumer skills and abilities by involving them in decision making and goals setting; it encouraged independence by focusing on building on strength and physical fitness; and it enhanced community connectedness through joint activity.

This and other examples provided in the resource will be further explored, particularly to gain a sense of longer-term outcomes from the various co-production approaches implemented.

COTA Australia, 2014, *The voice of consumers in Home Care: A Practical Guide.*

COTA Australia was funded by the Department of Social Services to undertake the Home Care Today project¹¹⁰, which provides a resource hub for new ideas and choices in home care. The project was guided by a Steering Committee representing providers and consumers

This Practical Guide has been adapted from a publication by the Adelaide Women's and Children's Hospital in 1996 to reflect current practices, technologies and the push to engage with consumers, particularly with the introduction of consumer-directed care in aged care. While targeted at home care, this guide provides a range of practical tools and tips that could be more broadly incorporated into new resources for providers.

It details the benefits of consumer engagement and the key success factors, which align with those detailed in the broader literature but are tailored to the aged care sector. It also uses the IAP2 Spectrum of participation to illustrate the different levels of engagement and how they could be applied in aged care. The Guide provides a tool for assessing an organisation's level of consumer participation, checklists to start implementing consumer engagement and activities to facilitate consumer engagement.

COTA Australia, 2014, *Co-creating Value: Lessons learned from Home Care Today's action research inspired co-production projects.*

This report outlines the outcomes and lessons learned from the 2014 Home Care Today co-production initiative, involving three service providers. The three projects took place over 12 months and were based around engaging consumers in: developing consumer information to manage home care packages; participating in a consumer reference group to identify improvements to an organisation's home care delivery model; and co-designing a consumer-driven model for existing community aged care packages. Many challenges were experienced by the organisations involved, including in developing an understanding of co-production among participants, eliciting senior-level organisational buy-in, defining the project scope and timelines, and building the confidence, skills and knowledge to empower consumers to participate. Despite these challenges, outcomes were achieved (resources developed, advisory group established, workshops and training conducted) and the co-production process was seen to be of benefit, with most consumers reporting that if invited to participate in similar activities again they would.

COTA has identified a list of challenges for organisations to overcome in implementing co-production – this could be explored further as part of the new resources to find methods that overcome these purported challenges. It aims to support both aged care providers and consumers through providing information, resources, training and peer supports to implement and maximise opportunities stemming from consumer-directed home care.

110 COTA Australia, Home Care Today, [accessed at www.homecaretoday.org.au].

**Office for the Ageing, Better Together:
A Practical Guide to Effective Engagement
with Older People, Government
of South Australia**

This publication was designed to promote and support genuine engagement with older people in South Australia in the decisions and issues that affect them. While it is based on the SA Government publication 'Better Together Principles of Engagement', it specifically addresses stereotypes and common myths associated with older people and how engagement scenarios and methods (focus groups, forums, interviews, reference groups) can best be implemented for this cohort.

**Petriwskyj, A, 2017, *Client Engagement Toolkit: A Resource for Aged Care Staff*,
The University of Queensland**

In 2018, COTA Queensland conducted workshops for the former Australian Aged Care Quality Agency using this engagement toolkit, which was designed to guide aged care staff through the process of thinking about what client engagement looks like for the organisation, what is working well, and what needs to be improved. The toolkit assists with planning an improvement project, implementing the project and evaluating it. There are three components: Tool 1 – Need for Action, Tool 2 – Action Planner, Tool 3 – Monitoring and Evaluation. Questions and checklists, which guide staff through facets of consumer engagement, are easy to follow and facilitate the capture of relevant information about client perspectives, who needs to be involved and how. The tools prompt brainstorming and reiterate the importance of inclusivity and ensuring people are comfortable with the process. Short examples of innovative client engagement are included (e.g. wall snippets, a Guide to Care, Dementia friendly café). Following the workshops, further resources are being developed and will be released in 2019.

Health

Australian Commission on Safety and Quality in Health Care, 2011, *Patient-centred care: Improving quality and safety through partnerships with patients and consumers*, Sydney.

In 2010, Australian Health Ministers endorsed the Australian Safety and Quality Framework for Health Care, recognising consumer-centred care as the first of three dimensions required for a safe and high quality health system in Australia. This guide builds on the Framework and provides a number of system and service-oriented recommendations to foster consumer-centred care in healthcare organisations.

The guide is aimed at healthcare professionals, managers and policy makers seeking to re-orient their systems, services and practices to partner with consumers and their families and carers. It provides background information, resources and examples of consumer-centred approaches and in-depth analysis of the concepts and evidence within Australia and internationally. It also provides appendices to help organisations assess readiness to implement consumer-centred care and an annotated bibliography outlining the key references and sources of evidence.

This is a key resource in the healthcare sector that is directly applicable to the role of the Commission. It has been extensively researched and consulted on, with a range of resources analysed, including across different health services and states within Australia, different sectors and internationally.

Australian Healthcare and Hospitals Association (AHHA) and Consumers Health Forum of Australia (CHF), 2017, *Experience Based Co-design: a toolkit for Australia*.

This toolkit was published by the Australian Healthcare and Hospitals Association (AHHA) and Consumers Health Forum of Australia (CHF) in 2017. Drawing on resources from the UK and New Zealand 111 and Australian case studies, this toolkit was developed for the Australian context as part of the Co-design Initiative in 2016. It offers a methodology for implementing co-design in the Australian healthcare system that brings health workers and consumers together in an equal co-design partnership.

The experience-based co-design (EBCD) method originated in 2006 in the UK National Health Service (NHS), and the methodologies underpinning it draw on participatory action research, narrative and learning theory.¹¹² The toolkit describes the five stages of EBCD: planning; gathering the experience; understanding the experience; improving the experience; monitoring and maintaining the experience. It provides tools, tips and case studies from organisations across Australia and directs readers to a range of additional resources (including detailed guides, diagnostic tools, YouTube videos, etc.). The key point of difference in operationalising EBCD lies in the need to deeply understand consumer and staff experiences and emotions. Strategies to support service providers to do this include narrative based approaches (conversations and story-telling) and in-depth observations.

111 The Point of Care Foundation <https://www.pointofcarefoundation.org.uk> hosts a detailed EBCD toolkit including step-by-step guide and films demonstrating lessons, tips and experiences relating to EBCD. In New Zealand, a healthcare co-design online toolkit (hosted by Waitemata District Health Board) can be found at: <http://www.healthcodesign.org.nz/tool-kit/>

112 Dimopoulos-Bick, T, Dawda, P, Maher, L, Verma, R and Palmer, V (2018) Experience based co-design: Tackling common challenges, *The Journal of Health Design*, Vol 3, No 1, p.86

This toolkit is widely acknowledged and commonly cited as a resource for good practice in co-design. It provides a comprehensive and practical guide to implementing EBCD and could be expanded and adapted to better suit the aged care sector.

NSW Agency for Clinical Innovation, 2017, *Patient Experience and Consumer Engagement: A Framework for Action*, Sydney.

The NSW Agency for Clinical Innovation (ACI) works with clinicians, consumers and managers to design and promote better healthcare for NSW. This Framework was developed using a co-design approach, involving members of the ACI Consumer Council from its conception and at all stages of development. It promotes meaningful consumer engagement and the capture and use of patient, carer and staff experience in health care provision and improvement to support NSW Health to deliver consumer-centred care. The Framework provides information, guidance and resources to enable this approach. While targeted to the NSW Health sector, the principles are consistent with those highlighted in the broader literature.

The ACI also has an online, experience-based co-design toolkit 113, aimed at healthcare settings. This toolkit is based on EBCD principles and has been used to build partnerships and facilitate health service improvements in six different health settings in NSW. The website provides personas, storyboards, questions, empathy maps, experience maps, experience questionnaires, and journey maps for use in different consumer engagement contexts. These tools could be readily utilised and adapted to the aged care sector for inclusion as a part of new resources for aged care providers.

SA Health, 2013, *Guide for Engaging with Consumers and the Community: a practical toolkit to assist health care services to implement A Framework for Active Partnership with Consumers and the Community*

The SA Health Guide for engaging with Consumers and the Community was developed through collaboration within SA Health and with other key stakeholders, including the SA Safety and Quality in Health Care, Consumer and Community Advisory Committee and consumer organisations.

It is a practical tool to assist health care services to strengthen and improve consumer and community engagement processes. It provides instruction about the key elements and scale of consumer engagement (across the individual, service, network and system level) and uses the IAP2 Spectrum to summarise the key features of consumer engagement.

This guide is succinct and practical and includes a 'Methods selector table' to help service providers choose which method of consumer engagement to use (and their strengths and limitations and tips for use). It includes links to templates and checklists that can support service providers in planning to engage with consumers, communicating clearly with consumers, designing the consumer engagement approach, and implementing and evaluating it. The guide also provides comprehensive tools and performance indicators for auditing the success of a service provider's consumer engagement, which could be adapted to the aged care sector.

113 NSW Agency for Clinical Innovation, Patient Experience and Consumer Engagement, [accessed at <https://www.aci.health.nsw.gov.au/networks/peace>]

Western Australian Department of Health, 2017, *You Matter: A Guideline to support engagement with consumers, carers, communities and clinicians in health, Quality Improvement and Change Management Unit, Perth.*

The WA Department of Health collaborated with a working group including consumer and carer representatives and organisations in the following sectors: indigenous health; child health; mental health; disability; country health, and primary health. It was developed to support WA health service providers in their engagement with consumers, carers, communities and clinicians to improve health services.

The guideline outlines the key principles, process, tools and requirements for effective engagement including encouraging the sharing of ideas, options and collaborative decision making across planning, service delivery, policy, research, and quality improvement. It also provides specific guidance for engaging with vulnerable and harder to reach groups.

This guideline outlines a clear process for undertaking and evaluating co-design and consumer engagement in the health sector, which could be readily adapted to the aged care sector. It also includes a number of case studies, which demonstrate how these principles could be applied in different settings.

National Health Service (NHS) England, 2015, *Personalised care and support planning handbook: the journey to person centred care.*

This handbook was developed by NHS England and the Coalition for Collaborative Care and was co-produced with representatives from commissioning organisations, care practitioners, consumers, carers and policy experts. It pulls together lessons from a number of organisations and programs that have been working to implement consumer-centred care and in particular, draws on outcomes from the Year of Care Program which has developed and tested models of care against implementation success criteria.

This handbook provides an introduction to consumer-centred care and contains links to practical guidance, case studies and theory on how to introduce personalised care and support planning in different settings. It is aimed at commissioners and care practitioners, and sets out what personalised care and support planning is and how to deliver it, including how it fits within the wider context of consumer-centred care, and can be used as a system enabler to help provide more proactive and co-ordinated care for people with long-term conditions and better support for self management.

The handbook establishes the drivers for implementing consumer-centred care, highlighting how the Year of Care program demonstrates that person-centred approaches not only benefit the individual, but can also lead to improvements for care professionals and commissioners. It includes examples of and links to consumer-centred care approaches from the Year of Care Program that have been evaluated and discusses the critical success factors.

The Point of Care Foundation, 2013, Experience-based co-design toolkit, London.

The Point of Care Foundation is a registered charity that has led, supported and trained participants in the EBCD approach since 2008. This detailed online EBCD toolkit includes a step-by-step guide to improving consumer experience of health care using EBCD.

The toolkit includes short videos from staff and patients involved in EBCD projects which bring to life the successes and lessons learned in undertaking EBCD. It also includes downloadable resources such as template forms, demonstrations, letters, presentations and other materials to support in planning and carrying out this approach.

The most recent version of the toolkit was produced in 2013 and incorporates feedback from staff and consumers involved in more than 60 EBCD projects across different countries (Australia, Canada, England, the Netherlands, New Zealand, Sweden and the United States) and in different settings (mental health, accident and emergency, palliative care and surgical units). This toolkit also includes an 'accelerated form of EBCD' which makes the approach more accessible to services with limited resources.

Key to this model of EBCD is filming people to record experiences (rather than using traditional surveys), then using the films to communicate with staff, rekindle empathy and build pathways to greater mutual understanding. In this co-design model, the participants are involved in co-managing the entire process, including the filming, managing consent and running events (working with staff experienced in EBCD throughout the process).

Think local act personal, Personalised care and support planning tool.

Think local act personal is an online tool hosted by the Social Care Institute for Excellence in London. It has been developed by a national partnership of more than 50 organisations committed to transforming health and care through personalisation and community-based support. The partnership spans central and local government, the National Health Service, providers, consumers, carers and family members engaged via a National Co-production Advisory Group.

This tool uses fictional characters to work through the stages of personalised care planning (context, preparation, conversation, documenting, making it happen, review). The characters have various physical, mental and social care issues. Their journey through the system and their interaction with different services, clinicians and professionals is designed to demonstrate how people with complex health and social care needs can experience a joined-up approach to personalised care and support planning that improves health and well-being outcomes.

Developing personas and workshopping through scenarios are referenced in a number of co-design resources. This is a strong example of an engaging visual website that puts the consumer at the forefront.

Engaging with diverse consumers

Brooker, D and Latham, I, 2015, *Person-Centred Dementia Care, Second Edition: Making Services Better with the VIPS Framework Edition 2*, Jessica Kingsley Publishers.

Given the complexity of interpreting and applying best practice consumer-centred care, the VIPS Framework: Person-centred Care for People Living with Dementia was designed to help providers of health and care services for people living with dementia to assess their relative strengths and weaknesses with regard to providing consumer-centred care. Using this information, the organisation can raise awareness of consumer-centred care, collect evidence for benchmarking and create an action plan for improvements.

The VIPS Framework¹¹⁴ was developed by the Association for Dementia Studies in the UK and launched in 2011. The VIPS Framework centres around four key elements: values (the importance of valuing human lives regardless of age or cognitive ability); individuals (focus on the unique person); perspective (understanding the world through the eyes of the person needing support); and social (seeing and responding to a person). The VIPS Framework consists of personal perspective indicators and socially supportive environment indicators which break consumer-centred care into 'manageable chunks'. The online tool includes 200 questions covering all aspects of care for the provider to complete and aims to identify the most useful resources and approaches. On completing the questions, the provider can then use the tools to implement changes and improvements to their organisation and the services they provide.

Goeman, D, 2016, 'Partnering with consumers to develop a Vietnamese Dementia Talking Book' in *Improving the healthy ageing experience of older CALD Australians: Integrating research, policy and practice*, Australian Mosaic: the magazine of the Federation of Ethnic Communities' Councils of Australia.

This article looks into considerations when working with culturally and linguistically diverse communities in co-design, including how to manage low literacy levels among the elderly population. The project describes how practitioners worked with 59 members of the Vietnamese community and 11 stakeholders from community health services and ethnic agencies to co-design and refine a talking book (bi-lingual, multimedia tool) to enhance understanding of dementia and strategies to help manage the condition. Key learnings from this project included the importance of working closely with older members of the Vietnamese community from the outset, using an interpreter, establishing language and ensuring cultural appropriateness of the content. Further testing of the talking book for usefulness and relevance (through focus groups and interviews) was a critical element of the project to ensure the product would be embraced by the community for which it was designed.

114 Care Fit For VIPS, The VIPS Framework, [available at: <https://www.carefitforvips.co.uk>].

Tan, L and Szebeko, D, 2009, 'Co-designing for dementia: The Alzheimer 100 project', *Australasian Medical Journal*, vol. 1, no. 12, pp. 185-189.

This article draws on a case study undertaken on the Alzheimer 100 project in the UK, to illustrate how a team of designers worked with healthcare professionals and consumers, to co-design consumer-centred services for dementia. Key stakeholders (consumers, carers, professionals and even healthcare cleaners) were involved in sharing experiences and challenges around specific issues and devising ideas and actions to address the issues.

Co-design methods included the use of communication platforms, storytelling and a co-design event. Storytelling and skill sharing were captured on film and used as a conversation starter at a Co-design Day, aimed at co-creating actionable ideas. Outcomes from the co-design process were utilised in Alzheimer 100, such as: developing a set of personas (real life stories of four characters living with dementia); a model for a safe wandering garden in residential care facilities; volunteer mentoring services for carers; and a 15 minute film capturing the daily life of people with dementia.

The article discusses the evaluation of the Alzheimer 100 project to determine outcomes for participants, including through undertaking interviews with staff six months after the project. Positive longer-term changes for staff included: improved understanding of the experiences of people living with dementia, skills transfer into daily professional practice and improved communication and engagement with residents. It attributed these outcomes to the co-design approach which drew out innovative ideas and built a sense of ownership.

Alzheimer's Australia, Valuing People.

Valuing People is a free online self-assessment tool developed by Alzheimer's Australia to provide organisations with the practical knowledge and tools to facilitate person-centred approaches and translate ideas into action. It was developed in consultation with people with dementia, their families, carers and community care providers. The tool is based on five guiding values (valuing people, autonomy, life experience, understanding relationships and environment) that are broken down into core elements or behaviours, which are further broken down into a set of actions. Guidance is provided on person-centred approaches and how to effectively work with consumers and their carers to involve them in a way that facilitates participation in care and decision-making.

This tool offers a range of performance indicators, which could be used to measure how effectively an organisation engages with and empowers consumers and staff.

Central Coast Local Health District (NSW), 2014, *Top 5 Toolkit Residential Aged Care Facilities: Integrating carer knowledge to improve care for residents with dementia, designed with the Clinical Excellence Commission as part of the Partnering with Patients program.*

The Top 5 initiative was initially piloted in hospitals in the Central Coast Local Health District as one approach to lessen anxiety, confusion and disorientation for patients with dementia and to acknowledge the value of the carer's knowledge in achieving this. This toolkit is tailored for residential care services and is based on the principles of partnership – recognising carers and residents as key members of the care team. Top 5 is the terminology used to frame the process of having conversations with carers and residents that enable development and ongoing review of personalised strategies to best support the resident. It is a model of consumer engagement that is directed at improving the quality of care and communication to benefit residents, carers and staff.

The Clinical Excellence Commission website has a section on consumer stories, with a series of videos that help health care staff understand what was good, what was bad and what could have made the experience more positive. The focus is on the individual receiving care, not the organisation.

ACON, 2014, *LOVE Consultation Report: Service needs and preferences of Older Lesbian, Gay, Bisexual and Transgender People, NSW.*

The ACON Ageing Initiative (ACON) is a New South Wales-based health promotion organisation specialising in HIV prevention, HIV support and lesbian, gay, bisexual, transgender and intersex (LGBTI) health. The Love Project (Living Older Visibly and Engaged) aims to create better conversations and improved social engagement with older LGBTI community members. [The LOVE project website](#) connects social groups, links to Facebook, promotes volunteering and includes a range of resources (e.g. the [Silver Rainbow Factsheet for developing an LGBTI-inclusive practice policy](#), which includes self-assessment tools and links to useful resources).

The Consultation Report describes outcomes from the LOVE Project's assessment of the needs and concerns of older LGBTI people in NSW in relation to ageing and aged care service provision. The four main issues of concern that emerged from the focus groups among older LGBTI people were: social isolation, finances, housing, inclusive services. Detailed insight is provided in relation to these areas, as well as physical and mental health issues and aged care service provision issues and preferences. The report presents diverse range of voices, including members of the LGBTI community using aged care services, representatives from aged care providers and peak bodies, all of whom were involved in contributing to the content through focus groups and community consultations.

ACON in partnership with NADA, 2017, *AOD LGBTIQ Inclusive Guidelines for Treatment Providers*, funded by Eastern and Central Sydney PHN.

This guide aims to increase the understanding of alcohol and other drug workers about the needs of LGBTI people and communities, their needs and how to provide an inclusive service response. One of the guide's inclusive practice principles is co-design and the guide reiterates that LGBTI people are resilient and resourceful, and a significant source of knowledge. A key message is that consumer participation and co-design is a process and there shouldn't be an expectation to 'get it all right the first time'. In taking an open approach to co-design (being guided by service users) some tips include acknowledging that the experiences of diverse gender and sexualities are not the same (i.e. one gay man does not and cannot represent the LGBTI community) and that there is great value in partnering with LGBTI organisations for subject matter expertise and to reach LGBTI communities.

Barrett, C and Malloy, 2018, *The Rainbow Makers: cultural safety and older LGBTI Australians*, produced for the National LGBTI Health Alliance.

This narrative-based resource traces the journey of Malloy, an older lesbian, as she navigates her way through the experience of discrimination by an aged care service provider. It highlights the importance of culturally safe aged care services and the power of aged care service providers to make a difference to the lives of lesbian, gay, bisexual, trans and gender diverse and intersex elders and older people. This resource can be used to by service providers to improve their understanding of the LGBTI consumer's experience and how they influence this experience, including by providing examples of culturally safe and inclusive services.

Additional resources

Aged care

Bisognano M, 2016, *New Models for Elder Care: Three ways Norway inspired me*, Institute for Healthcare Improvement.

Since 2012, Norway has implemented an approach to aged care emphasising reablement, helping people return to their ability to take care of themselves and their health. This article references the way interprofessional teams (occupational therapists, social workers, physical therapists, and nurses) work intensively with consumers needing rehabilitation in their homes, with the understanding that this support will drop off as the consumer takes over more and more of this care on their own. The approach is based not only on their clinical care needs, but what matters most to them – what health goals they most want to achieve. They look to build on consumers' assets, encouraging and enabling consumers to do things for themselves. The emphasis is on providing care with people rather than for them.

Buffel, T (ed), 2015, *Researching Age-Friendly Communities: Stories from older people as co-investigators*, The University of Manchester

This participatory guide tells the story of older people who were involved as co-investigators in a study aimed at developing age-friendly neighbourhoods in Manchester. It includes thoughts, practical tips, and critical reflections to inspire ways of rethinking how older people can be involved in research and social action (including participant observation, focus groups, participatory mapping, in-depth interviews and participatory learning and action). It is a relevant resource as it comprehensively documents the advantages, challenges, resourcing and methodology for co-producing a project with older people.

Carrie Hayter Consulting, July 2016, *Nothing about us without us – older citizens co-producing residential services – six key steps*.

Nothing about us without us is a brief paper, which identifies some of the key issues for older people, families and staff living and working in residential services in Australia. It includes six key steps for coproducing residential care services. The steps are based around engaging people in issues, building connections and creating a culture of active participation, so that the solutions to issues can be found collaboratively. Fostering social connectedness is also a key step in this process (residents are encouraged to lead activities and interest groups of their choosing) as is the education and empowerment of frontline staff.

Equal Arts, *HenPower*, Newcastle, United Kingdom.

Implemented in more than 40 care homes throughout the UK, HenPower is a project that cultivates creativity and active participation. In this instance, HenPower brings together older people and henkeeping to combat loneliness and depression and improve well-being. Lessons from this project included: the importance of empowering of older people to build positive relationships through activities that improve well-being, reduced loneliness and reduced depression; it helps care settings offering relationship-centred care to meet needs, embracing 'living with care' as opposed to 'caring for'; create change by supporting older people in care settings to get involved with schools, festivals and community events; support Resident and Relative Committees within care settings to be aspirational and provide meaningful activities which embrace creative ageing; provide social care staff with excellent skill transfer and professional development opportunities.

Global Centre for Modern Ageing, 10 May 2019, *Co-designing Aged Care in Strathalbyn: Outcomes Report*.

The Global Centre for Modern Ageing (GCMA) and the Australian Centre for Social Innovation have trialled the co-design of a new aged care precinct, to be funded with \$12 million by SA Health. Over 180 people from the Strathalbyn community have been involved in the project, including future residents, health practitioners and service providers in a series of interviews, co-design sessions and an open house community forum. This report summarises the views and experiences of the local community against six design principles (key elements of home and life that could be incorporated into the future aged care service and precinct). Of most relevance to consumer engagement were the recommendations in Design Principle: Valuing People, related to bringing out the potential for people to contribute to their own well-being and that of others. Service suggestions included developing new ways for volunteering, family carers to contribute as valued experts in their loved one's care, and considering shared and co-care models as potential approaches for formalising and growing existing networks and relationships.

Hayter, C, 2017, *Small steps, big changes: empowerment and inclusiveness needed for older Australians, Aged Care Insite, 8 March.*

This article promotes the idea that older people have rich histories and strengths that can be used productively to shape the design and delivery of aged care services. Examples of inspiring projects are given to demonstrate the ways that services can support the active participation of older people and their allies, and show that small steps can lead to big changes. These examples include: a photography exhibition capturing the changes, challenges and resilience of older age at the State Library of Queensland (all images taken by residents, staff and the researchers through a co-design project), the Dementia-Friendly Kiama project (working with the local community, people living with dementia and their allies to create an inclusive community); and the 300 member Waverton Hub, a collective of residents in Sydney who help each other to enjoy life and live in their homes and community for as long as possible. Those seeking to try new forms of consumer engagement with older people are directed to Client Engagement Toolkit and CommunityWest's Step Forward – Together project.

Helping Hand, 2012, *Consumer and Engagement Framework*.

This Framework provides an example of a statement committing a service provider to the principles of consumer engagement and the centrality of consumer participation in service development and delivery. It describes a spectrum of participation (based on IAP2), through five stages, starting with informing consumers, through to consulting, involving and collaborating with consumers, ultimately empowering them. The Framework is put in to practice by seeking consumer engagement across the areas of policy, planning, service delivery, research and evaluation.

InnovAgeing, 2019, *Whiddon introduces MyLife and ASCOT in care planning.*

An example of an initiative aimed at improving a provider's ability to gather meaningful information from care recipients in order to more effectively measure well-being outcomes and improve care planning processes. Whiddon introduced the Adult Social Care Outcomes Toolkit (ASCOT) tool (a suite of instruments designed to measure social care-related quality of life) for a 15 month trial period from 2016 to 2017. As registered nurses had reported they were not confident initiating and conducting conversations around emotional and social needs with residents, the ASCOT tool was trialled to improve the 'circle of care' interview methodology and allow people with dementia to participate. Reported benefits of the new approach Whiddon took were: systematic integration of thoughts and feedback from care recipients into their care planning; empowerment for staff, care recipients and families as the new relationship-based approach to gathering information encouraged them to speak openly; and tailored initiatives that were raised in conversations were implemented and followed up.

Jenkins, K, Eade, R, Bartsch, C and Yang, E, 2017, *Consumer Directed Care Reform: Consumer Engagement Toolkit, project undertaken as part of Engaging Young Leaders on Aged Care & Community Boards.*

The toolkit is intended to bring together examples of best practice in consumer engagement strategies to inform boards and executives of small to medium sized aged care providers – it is a starting point for tailoring a consumer engagement strategy, in the context of the implementation of consumer-directed care. It describes the ways that services providers will need to think about engaging new and existing consumers to ensure that they retain a strong presence in the market and provide a strong service offering.

Jordan M, Rukas G, 2017, *Emerging Ageing: co-designing responses to positive ageing for new and emergent migrant communities, Project Report, Ethnic Communities' Council of Victoria and Per Capita.*

This report outlines a co-design project whereby members of emerging migrant communities were involved in conversations about their experience of ageing and taking part in as to how the experience of ageing may be improved. Co-designed recommendations were made to maximise positive ageing for these communities.

McCormack, B, Dewing, J and McCance, T, 2011, 'Developing Person-Centred Care: Addressing contextual challenges through practice development', *The Online Journal of Issues in Nursing*, vol. 16, no. 2.

Professor Brendan McCormack, Associate Director, Centre for Person-centred Practice Research, has many publications. The focus of his research is enablement, through a person-centred lens. He was a keynote speaker at The International Association of Gerontology and Geriatrics European Region Congress 2019 held 23–25 May 2019 in Gothenburg, Sweden.

This article identifies key issues relevant to the development of person-centred care in residential aged care. It includes a case study of a two-year program conducted in Ireland (2007-2009) in which a framework for person-centred practice was implemented across 18 residential aged care units and the processes and outcomes were evaluated. The program involved nursing staff, health care assistants, housekeeping, catering and administration staff. Participants met with a facilitator for a skills development day every six weeks and this evolved into internal discussion groups and meetings as action plans and activities were implemented. As understanding of the PCC framework (and what it looks like in the workplace) and the culture changes required to implement it grew, a range of activities were undertaken, including awareness-raising activities for staff, residents and families, participating in active learning directed at increasing involvement of/connectedness with residents. Key findings from this program related to increased competence of staff in using

a PCC approach, development of interpersonal skills and change in nurses' perception of caring. For residents and families, the data demonstrated important qualitative changes in care practices and these changes were particularly evidenced in residents' narratives. For example, improvements made in the range of activities and choices available for residents reduced ritual and routine, increased involvement in decision making, and contributed to improved quality of engagements between staff and residents. Increased hopefulness in the way residents felt they were cared for was documented, as was a greater sense of belonging and connectedness in year two, as staff got to know individual histories/narratives and understand people in a more meaningful way.

My Home Life, 2019, *Toolkit: Conversations for Quality Improvement*.

My Home Life is a UK-wide initiative promoting quality of life for those living, dying, visiting and working in care homes for older people, through relationship-centred and evidence-based practice. The toolkit centres around empowering people to engage in caring conversations. There is a fact sheet with tips for starting the journey of quality improvement in care homes, and a series of 36 Emotion Cards (with words such Alarmed, Angry, Surprised, Nervous, Calm, Safe) and 40 Touch-point Cards (with statements such as Involvement in decisions, Talking with staff, mealtimes, The routine of the place, Speaking up) for use as conversation prompts and to help staff to begin a discussion based around feelings and what could be done to improve experiences.

Mulvale, G, Moll, S, Miatello, A, Robert, G, Larkin, M, Palmer, V, Powell, A and Gabel, C, 2018, *Co-designing public services with vulnerable and disadvantaged populations: Insights from an international collaboration*, Service Design Proof of Concept Politecnico, Milan.

This report discusses the outcomes from a two-day symposium in 2017 that brought together health care and service professionals to identify challenges and suggest improvements to co-design and co-production approaches when working with vulnerable and disadvantaged populations. Common co-design challenges identified across varied projects included issues with initial recruitment, securing ongoing participant engagement throughout the co-design process, and power imbalances. Other challenges included unpredictability of participant health status and insufficient funding for projects. It was recommended that core principles drive co-design projects rather than a series of rigid steps, as this will better respond to participants' needs.

Rahman, M, McDonald, E, Edvardsson, K, Pascoe, L, Lood, Q, Jokwiro, Y and Edvardsson, D, 2018, Psychometric analyses of the person-centred climate questionnaire-Family (PCQ-F) in Australia, Norway and Sweden, *Innovation in Aging*, vol. 2, pp. 127-128.

This study aimed to assess the psychometric properties of the Person-centred Climate Questionnaire-Family version (PCQ-F) in residential aged care settings. The PCQ-F questionnaire was distributed to a sample of 178 family members in three residential aged care facilities in Australia, Norway and Sweden in 2016. Findings of this study indicate that the PCQ-F can be used reliably in residential aged care settings to assess person-centredness of the climate as perceived by family members. The tool can guide healthcare managers, workers and stakeholders to analyse and intervene on the psychosocial climate within long-term care facilities. Full details of this study are not available.

Royal Commission into the Aged Care Quality and Safety Commission, May 2019, Statement of Professor Henry Brodaty.

Professor Brodaty notes that while person-centred care has been associated with high quality care in Australia and abroad over the past two decades, task-orientated rather than person-orientated approaches continue to prevail in many residential care services in Australia. Change to a more person-centred care approach will require leadership and willingness to embrace change in practice and attitudes and incorporated into standards expected of service providers and evaluation by assessors by continuing to talk to residents, families and staff.

Royal Commission into the Aged Care Quality and Safety Commission, 27 April 2019, Statement of Merle Valma Mitchell AM.

Merle Mitchell AM is an advocate for the rights of older people receiving aged care and has presented her story to The Royal Commission into Aged Care. She explains the difficult and emotional decision-making process involved in choosing residential care, and the subsequent sense of loss (of privacy, independence and community) experienced by older people on moving into residential care. Ms Mitchell emphasises the difficulties in coming to terms with the regimentation of meals, showers and other activities and the need for staff to be educated about loss, and how to communicate with elderly people. She also reiterates the importance of listening to consumers if positive changes are to be made and that respect, dignity and diversity are central to providing person-centred care.

Wright, R., et al, 2018, 'Using experience-based co-design with older patients, their families and staff to improve palliative care experiences in the Emergency Department: A reflective critique on the process and outcomes', *International Journal of Nursing Studies*, vol. 68, pp. 83-94.

An Emergency Department in a large teaching hospital in the UK used experience-based co-design with older patients, their families and staff to improve palliative care processes. Co-design methods included observation, staff interviews, focus groups with staff members, filmed semi-structured interviews with palliative care patients and their families and a co-design event involving staff, patients and families. The study successfully identified quality improvement priorities leading to changes in Emergency Department-palliative care processes. Further outputs were the creation of a patient-family-staff experience training DVD to encourage reflective discussion and the identification and application of generic design principles for improving palliative care. There were benefits and challenges associated with using EBCD in this setting. Benefits included the flexibility of the approach, the high levels of engagement and responsiveness of patients, families and staff, and the impact of using filmed narrative interviews to enhance the 'voice' of seldom heard patients and families.

Health sector

Auckland District Health Board, 2019, Health Service Co-design Toolkit.

This toolkit is an online resource designed for use by operational, clinical or quality staff seeking to involve patients in improving healthcare services. It includes templates to assist with proactively establishing and maintaining meaningful relationships with patients in working on service improvement and developing new processes. Some of the activities recommended for the co-design process include start-up and planning workshops; patient shadowing and journey mapping; experience-based surveys; gathering patient stories and developing a stakeholder needs table; scenarios and personas. In the toolkit, all of these activities are supported by information about when and how to use it, questions, key considerations and templates.

Consumers' Health Forum of Australia, The Real People and Real Data Toolkit.

The CHF Real People, Real Data Project was funded by the Commonwealth Department of Health. This toolkit provides straightforward advice and templates for health services, policy makers and consumer organisations that want to gather, analyse and use consumer stories about their healthcare to guide their strategic decision-making. It outlines the 5 steps involved in planning a storytelling project and refers to the consumer-centred framework for storytelling as the 'patient life journey'. There are detailed tips and prompts for conducting interviews and for subsequently analysing and presenting consumer stories to shape decision-making, which are visually distilled into 'The Health Experience Wheel'.

Department of Health and Human Services, 2019, Stakeholder Engagement and Public Participation Framework and Toolkit, Melbourne.

This Framework and Toolkit provides a guide on how the Department engages with the health and human services sector, stakeholders and the community to achieve quality outcomes and delivers on its Strategic Plan. It outlines the fundamental principles and elements that underpin good engagement practice and includes a step-by-step guide and 10 pages of practical templates to develop and implement a successful stakeholder engagement process. The templates work through purpose, identifying and understanding stakeholders and sought-after levels of participation, how to develop an activity plan, conduct risk assessment, and implement, monitor and evaluate based on feedback.

Foroushani S, Travaglia J, Eikli M and Braithwaite J, 2012, *Consumer and community engagement: A review of the literature*, Australian Institute of Health Innovation, Agency for Clinical Innovation and University of NSW, Sydney.

This literature review was conducted in 2012 and examines the evidence for consumer and community engagement, maps out the context at that time and identifies the gaps in regarding the best way to engage consumers and communities in healthcare services and research. An extensive review of the literature was undertaken with 10,078 findings assessed for relevance before being distilled to include 117 studies.

The review proposes a model to facilitate implementation of consumer and community engagement in healthcare that identifies eight different areas that need to be explored: aim; type of activity; participants; preparedness; engagement methods; measurement; barriers; facilitators.

Fraser, J, 2013, *Little Book of Cultural Tips*, Diversicare, Brisbane.

A guidebook of tips and information for staff involved in community, aged care and health industries in the provision of culturally appropriate support and care. It encourages reflection on how communication takes place and suggests strategies for improving communication, in a culturally sensitive way. It is particularly relevant to consumer engagement in the home care setting, as it includes details about gathering information about client needs, arriving at and entering clients' homes, completing tasks, and providing follow up service.

Goodrich J, 2018, 'Why experience-based co-design improves the patient experience (editorial)', *The Journal of Health Design*, vol. 3, no. 1, pp.84-85

Goodrich contends that in the health setting, equal involvement of patients and staff in a co-design process is a positive outcome in itself, as a great deal can be gained just from working together. Co-design is motivating for staff and patients when they are supported to work alongside each other in a focused way, and the physical presence of patients in the project reminds everyone who the designed improvements will be for. Co-design can be empowering and is more likely to result in sustainable change when patients have contributed to the design and testing of solutions.

Gustavsson, S and Andersson, T, 2017, 'Patient involvement 2.0: Experience-based co-design supported by action research', *SAGE journals*.

This Swedish case study demonstrates the principles of EBCD storytelling in action.

This article is based on findings from two EBCD projects in paediatric care processes in a Swedish hospital. Both projects lasted for about nine months and were inspired by EBCD and action research (i.e. healthcare professionals drawing upon the experiences of patients and their families in order to truly reflect on patient needs and involve them in co-production to bring about sustainable change).

A key aspect of this example was that patients and healthcare professionals had the opportunity to speak about their own experiences and reflect collaboratively about the narratives to identify improvements. Patients referred to the process of communicating 'eye-opening stories' as giving them more attention and dignity, and professionals felt that it opened up their vision of areas where change was needed and stimulated creative ideas. While there was some anxiety (from professionals) around the new role that patients and their families played in the EBCD process, views changed over the course of the project as the benefits of drawing and reflecting on a variety of perspectives in a more equal relationship became apparent.

Maher, L, Hayward, B, Hayward, P and Walsh, C, 2017, 'Increasing patient engagement in healthcare service design: a qualitative evaluation of a co-design programme in New Zealand', *Patient Experience Journal*, vol 4, no. 1, article 4.

The Health & Quality Safety Commission New Zealand commissioned Ko Awatea, an innovation and improvement centre, to deliver a co-design program to nine teams of healthcare providers. The objective of the co-design program was to support and enable patient engagement and participation across the health and disability sector. Participating teams received training, guidance and mentorship in Experience Based Design (EBD) methodology. The programs were evaluated. Key findings included the importance of tailored strategies for approaching patients and capturing their experiences, pre-existing relationships and continued rapport building between patients and health professionals, good communication throughout the project, and planning and visibility of outcomes.

Narino, S, 27 November 2018, *Is Co-Design the key to humanizing health care?*, Institute for Healthcare Improvement.

This case study describes a co-design approach adopted by a paediatric hospital in Columbia to transform the care provided to around 14,000 children per month.

The study used a range of co-design tools, including experience and empathy mapping, one-on-one meetings, storytelling and narratives and workshops. Experience-based design was used to enable staff to partner with families and patients to develop better ways to provide care (through identifying what patients and their families feel when they use a service and when they feel it). The project was considered a success, with staff, patients and families reporting that the process was powerful and meaningful. With 10 per cent of staff trained in humanisation strategies, staff reported feeling happier and turnover dropped to under two per cent.

Key to the success of this project was ongoing education of staff and involvement of patients and families in driving the project.

NESTA, *People powered health co-production catalogue*, London.

Nesta is an independent charity based in the UK and supported by a financial endowment. Nesta has developed an online catalogue bringing together a range of case studies, resources and other information on co-production in health settings as well as in other sectors, internationally. The catalogue is designed to enable practitioners to learn about co-production and reflect on their own practice. It includes a case study, Partnerships for Older People Projects from the UK 2006 to 2009.

NHMRC, 2006, *Guide to effective participation of consumers and communities in developing and disseminating health information*, Canberra, Australian Government.

NHMRC is Australia's leading expert body in health and medical research and aims to ensure Australians have access to evidence-based, authoritative health advice. One of their key requirements for developing advice is the engagement of consumers to whom their advice applies.

This guide recognises consumers as people who have lived experience of a health issue, which may include patients, their friends, families, carers, members of the general public, or people who represent the views and interests of a consumer organisation. It notes that representation by carers or consumer advocates is especially important for any consumer group that might have trouble getting their voices heard in their care, e.g. people with dementia or mental ill-health.

The NHMRC notes that guidelines are designed to improve the health and well-being of consumers and that they should be involved in decision making on health issues that affect them. Consumers are best placed to ensure that recommendations made for them or about them are consistent with their values and preferences—this is done by sharing their lived experience with developers.

Realpe A and Wallace I, 2010, *What is co-production?*, The Health Foundation, London.

This paper provides a working definition of co-production in a health context, based on sharing of information and shared decision making between service users and providers. Co-production is described as requiring users to be experts in their own circumstances and professionals to move 'from being fixers to facilitators'.

Consistent with other resources on co-production, there is an emphasis on the reallocation of power implicit in co-production and the importance of training front-line professionals, so they are empowered to work with these new relationships.

Reid, P, 2015, *Why we need a co-design approach to transitional care, Hospital and Healthcare*

This article suggests that increasing the number of restorative care places for transitional care alone will not ultimately impact on the capacity of older Australians to remain living at home longer. Rather, a co-design approach needs to be taken to reviewing the current transfer of care processes and systems to make the journey more seamless for consumers. In this context, co-design is described as engaging users of products and services in the design process to lead to improvements and innovation (involving all players at different intersection points of the transitional care spectrum).

Santana M, Manalili K, Jolley R, Zelinsky S, Quan H and Lu M, 2018, 'How to practise person-centred care: A conceptual framework', *Health Expectations: an International Journal of Public Participation in Health Care and Health Policy*, vol. 21, no. 2, pp. 429-440.

This framework describes a conceptual framework as a 'roadmap' to guide healthcare systems and organisations in the provision of person-centred care across various healthcare sectors. The overarching components of this framework are: Structure (with detail about creating a person-centred care culture at the organisation level), Process (at the patient-healthcare provider level, cultivating communication and engaging patients in managing their care) and Outcome (patient-reported outcomes and access to care).

Steen, M, Manschot, M and De Koning, N, 2011, 'Benefits of Co-design in Service Design Projects', *International Journal of Design*, vol. 5, no. 2, pp. 53-59.

This article defines co-design as bringing together diverse experts such as researchers, designers or developers, and customers and users, who are experts of their experiences, to collaborate. It includes a case study, 'Co-design with Elderly People, to Develop Concepts for Health Care Services'. This case study was about developing and evaluating new service concepts, with the goal of helping people to better and more actively participate in their social networks. It also looks at co-design techniques including interviews, diary studies, workshops and the way implicit assumptions were challenged during the co-design process.

**University of Gothenburg, GPCC
– Centre for person-centred care,
*The PCC Game app – learn by playing.***

This application was developed on behalf of the University of Gothenburg Centre for Person-centred Care (GPCC) in Sweden, a research centre that aims to spread knowledge about implementing person-centred care as an approach in various health care settings around the world. The game is set up as a map, where the user can choose different tasks. The tasks are either mini-games or content that stimulates reflection. The user is also encouraged by the game to test new ideas directly in daily activities and think about the outcome. One example of a mini-game is that the user can meet a fictitious care recipient, navigate through dialogs to then create a health plan together with the care recipient.

The website includes narratives, resource links and a series of research articles included on the GPCC website relating to PCC.

**Victorian Agency for Health Innovation
and Safer Care Victoria, *Online resources.***

Safer Care Victoria (the Victorian healthcare quality and safety improvement agency) works with the Victorian Agency of Health Innovation to develop tools, including training and recruitment guides to help organisations providing healthcare services to improve patient engagement and experience.

Though some resources will not be available until December 2019 (i.e. resources to support shared decision-making strategies/equitable and diverse consumer engagement), the tools currently available online include:

***Partnering in healthcare: a framework
for better care and outcomes***

This framework outlines a new partnership and consumer participation approach to drive positive change in public health services across Victoria. Developed using a co-design approach.

***Partnering in healthcare
self-assessment tool***

This self-assessment tool supports the framework, enabling organisations to reflect on strengths and challenges (with respect to their current levels of consumer engagement) and identify areas for improvement across direct level, service level and system level. There are five different templates matched to the relevant Quality Standard and titled: Personalised and holistic; Working together; Shared decision making; Equity and inclusion Effective communication. Each template includes a description of what consumers said they wanted in relation to the Standard, as a guide for organisations assessing their own performance. In support of this tool there is a one-page Partnering in healthcare statement of intent for organisations to complete, which enables them to identify two key areas they will focus on, with endorsement from their health service board.

Adult experiences of care in public hospitals 2016: Results from the Victorian Healthcare Experience Survey, Patient Survey Series 2018

The Victorian Healthcare Experience Survey collects, analyses and reports the experience of over 30,000 people attending Victoria's public healthcare services. The results are provided to health services and the Agency each quarter. The Agency, Safer Care Victoria and health services use the results to identify areas that require improvement. Health services are required to complete Quality accounts and are using patient feedback provided through the survey to make quality improvements.

Victorian quality account: Reporting guidelines for 2017-18

The Victorian quality account was introduced in 2016 as part of the evolving quality and safety reporting landscape, placing emphasis squarely on the importance of transparency and accountability in public reporting. Of relevance is the guidelines in relation to (Standard 2 Partnering with consumers), relating to consumer, carer and community participation. The guidelines emphasise that public health services should report on how they engage with consumers to identify three patient experience priority areas, and progress made to address improvement areas. They must also report on results relating to positive patient experiences responses from the Victorian Health Experience Survey, in a framework of result – target – action and outcomes. All services must report on how the organisation actively contributes to building the capacity of consumers, carers and community members to participate fully and effectively in their healthcare.

Victorian Government Department of Health, 2010, Supporting people in care relationships, Melbourne.

This guide is designed for management and staff working in services supporting carers. It contains ideas to spark creativity in the development of new carer support models by way of examples of non-traditional programs that have been trialled in Victoria. Each example includes a description of what took place, who was involved, the benefits, challenges and potential ideas that can be drawn out for others to implement. Examples centre around programs that improve the health and well-being of carers (i.e. physical activity, support groups, diversional therapies, retreats, community cafés) and some ways to support different communities (Indigenous, culturally and linguistically diverse, rural). A key message that can be drawn from the examples is that caring is not a static job and services need to be innovative and flexible in their approach to helping carers.

Other sectors

Coppola, M, Nurnberg, C, Poulimenos, D and Swanson, M, Lessons physician groups can learn from the hospitality industry, Huron Consulting

The hospitality industry places great emphasis on creation of loyal customers. This article suggests that some elements of customer relationship management in hospitality could be incorporated into the healthcare industry. For example, a concierge could be employed in physician practices to enable patients to ask questions, connect with community resources and seek additional support (essentially personalising the services, just as hotel concierges do). Other examples given are: loyalty programs (a coupon to buy vitamins at a local chemist, or a celebration for reaching a weight loss goal) and leveraging technology (text alerts when appointments are running late). In building customer loyalty and satisfaction consistent, small gestures over time can have the biggest impact.

Integrated Resource Framework (IRF) Co-production Learning Template, 2008, developed as part of the Shifting the Balance of Care Delivery Group project

This learning template was prepared for the Integrated Resource Framework (IRF) program in Scotland, a program established in 2008 to address a perceived lack of shared resources available to guide informed and evidenced decision making by care partners. It is designed to help people reflect upon their practice by asking a number of questions that can guide people in thinking through how they might effectively structure learning from their work. It provides a guide to questions that might be asked when writing up case studies on co-production.

Think local act personal, May 2019, *Podcast: Co-production and the art of conversation.*

This podcast includes a conversation with Sally Percival, Chair of Think Local Act Personal, regarding her family experiences of co-production in health and social care settings. Co-production is described as being about creating equality between people who use services and those responsible for delivering services. Examples provided of people coming together as equals were based around developing relationships and having good conversations to identify solutions to problems. For genuine sharing of power, the users of services need to be encouraged to sit at the table and make decisions about their lives, and in many instances their confidence and skills need to be built so that they can make decisions. The overarching message is that while the concept may seem straightforward, we need to start somewhere in encouraging different types of conversation to personalise care services.

Social Care Institute for Excellence, 2013, *Co-production in social care: What it is and how to do it, London.*

This is a guide to co-production in social care and how to develop co-productive approaches to working with people who use services and carers. It describes co-production as a kind of jigsaw model to manage change, with the four key pieces being: culture (the beliefs and values that define an organisation and the way that it works), structure (the way the organisation is arranged and the systems it has set up to carry out its work), practice (how the organisation and the people who work for it carry out their work) and review (monitoring how the work is carried out and the outcomes or impacts that result from the work). The Guide includes practice examples to demonstrate how other organisations have co-produced projects.

Engaging with diverse consumers

Australian Institute of Aboriginal and Torres Strait Islander Studies, 2017, *Module 8: Engaging with Aboriginal and Torres Strait Islander Communities*.

This is a list of recommended resources, websites and videos for practitioners seeking to learn about development practice and co-design methodologies as they apply to working with Aboriginal and Torres Strait Islander communities. A range of topics are covered, including how to explore conditions for effective relationships with Aboriginal and Torres Strait Islander communities, how to facilitate conversations on Indigenous needs and aspirations, the difference between listening and hearing and alternative ways to look at conflict resolution.

Australian Government, 2012, *National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy*, Department of Health

The purpose of this strategy is to inform the way the Australian Government supports the aged care sector to deliver care that is sensitive to and inclusive of the needs of LGBTI people, their families and carers (ensuring that LGBTI people have the same opportunities and options in aged care that all Australians have). It includes five principles (inclusion, empowerment, access and equity, quality, and capacity building) as a framework to help aged care organisations consider their own LGBTI-inclusive practices and a series of strategic goals and actions for the Department of Health to report progress against.

Chenoweth, L, Stein-Parbury, J, Lapkin, S Wang, A, Liu, Z and Williams, A, 2019, 'Effects of person-centered care at the organizational-level for people with dementia. A Systematic review', *PLoS One*, vol. 14, no. 2.

This review looked at the effectiveness of organisational level person-centred care for people living with dementia in relation to their quality of life, mood, neuropsychiatric symptoms and function. Of particular relevance, it examined 12 studies, and noted that all of the studies which trialled implementing person-centred care approaches focused on developing direct care staff and carer manager knowledge, attitudes and skills through staff training, complemented by skills modelling and supervision by person-centred care champions/coaches, and managerial leadership at systems-level. Care staff were encouraged to seek out information on individual life stories, personalities and achievements and to employ this knowledge in delivering care.

Dahlberg, T, 2018 Engaging patients with culturally competent care, Studer Group, 15 October.

This article emphasises the importance of cultural competence in connecting to patients' hearts and minds when providing healthcare. A key message for service providers is to 'Meet patients where they are and not where we want them to be', acknowledging and honouring cultural preferences and encouraging patients to tell their own stories, and express their desired path to wellness. Leadership is also referenced as key in building a culturally competent workplace, as is listening to community needs. One example given was of care provided in a barbershop in Chicago, as it was a favourite gathering place for African American males.

Draper, R (Bolton Clarke), 2018, Using a co-design approach to support aged care workers to understand and respond to the needs of transgender and gender diverse people.

Bolton Clarke is a large national provider of at-home support and residential aged care services. This article documents a transgender and gender diverse project undertaken, based on a co-design approach partnering with consumers (for which Bolton Clarke received a 2017 Better Practice Award from the Australian Aged Care Quality Agency). The objective of the project was to develop and evaluate resources (a consumer digital diversity story) to support aged care workers to meet the needs of trans and gender diverse consumers using a co-design approach. Outcomes were that the diversity story was seen as a potentially useful resource for aged care workers to more effectively understand and respond to the needs of trans and gender diverse consumers. The co-design process reportedly enhanced the usefulness of the resources and sent a clear message across the organisation that equity of access was important.

Federation of Ethnic Communities' Council of Australia, 2015, *Review of Australian Research on Older People from Culturally and Linguistically Diverse Backgrounds*, funded by the Australian Government Department of Social Services.

This review describes the existing evidence base about culturally and linguistically diverse Australians and identifies gaps in the research. It covers four broad topic areas: older people from diverse backgrounds; older people from diverse backgrounds with dementia; ageing and mental health issues for people from diverse backgrounds; and diverse carers and carers of older people from diverse backgrounds.

A key message is that it is essential to recognise that older people from culturally and linguistically diverse backgrounds in Australia are not a homogeneous group; they encounter different outcomes based on individual experiences and backgrounds. This diversity means that understanding and meeting the needs of Australia's older people from culturally and linguistically diverse backgrounds is highly complex. The report provides a basis from which service providers and policy makers can consider targeted research and begin to examine necessary and appropriate strategies for practice improvement and change.

Rodgers, P, 2016, 'Co-designing with people living with dementia', *International Journal of CoCreation in Design and the Arts*, Vol 14, Issue 3, pp.188-202.

This article details research undertaken in collaboration with Alzheimer Scotland, looking into how disruptive design interventions can break the cycle of traditional 'ways-of-doing'. The 'Disrupting Dementia tartan co-design project' in 2014 had as its objective to help change the perception of dementia by showing that people with dementia have much to offer and were capable of designing a new product that could be sold across the world to fundraise for dementia awareness. Project employed co-design approach, emphasis on empowerment, sharing experiences and capacity building.

Rosvik, J, 2013, *Development, evaluation and the effects of the VIPS practice model for the person-centred care of patients with dementia. An intervention study in Norwegian nursing homes*, Akademia Publishing: Series of dissertations submitted to the Faculty of Medicine, University of Oslo No. 1808

The overarching aim of this thesis was to translate the values of PCC into practical daily care by use of the VIPS framework and to examine whether a VIPS Framework model could be implemented in a Norwegian residential care setting. Fourteen residential care services in Oslo, with a total of 40 wards and 624 patients with dementia participated in the study.

The VIPS practice model (VPM) study incorporates an education and coaching approach, clearly defines staff roles, and is based on regular structured team work, supervision and supportive management (to ensure the staff are aligned in a person-centred focus).

A 10 month cluster randomised controlled trial (RCT) was conducted to examine the effect of the VPM together with Dementia Care Mapping (DCM), another model based on PCC. The 14 residential care services participating in the trial were randomised into three groups – one used DCM, one used VPM and one acted as a control.

Relevant staff received training in how to implement DCM and VPM. For the services implementing VPM, registered nurses and service directors attended a basic three-day training course, including DVDs illustrating the perspective of the person with dementia, role playing and planning for implementation in each service. Throughout the trial, researchers undertook observations, recorded consumer/staff interactions and held feedback sessions with care staff.

The effectiveness of interventions was measured by the researchers through a number of assessment tools: the primary outcome was change on the Brief Agitation Rating Scale (BARS); secondary outcomes were changes on the 10-item version of the Neuropsychiatric Inventory Questionnaire (NPI-Q), the Cornell Scale for Depression in Dementia (CSDD) and the Quality of Life in Late-Stage Dementia (QUALID) scale.

The results indicated that implementing PCC through the VPM might reduce the total amount of neuropsychiatric symptoms, psychotic symptoms and depression in patients with dementia.

Dreise, T & Mazurski, E, 2018, *Weaving Knowledges: Knowledge exchange, co-design and community-based participatory research and evaluation in Aboriginal communities, Literature Review, Case Study and Practical Tips, Aboriginal Affairs New South Wales*

This paper explores the ‘threads’ of co-design and community-based participatory research (CBPR) as they relate to evaluation and research in Aboriginal contexts. It describes the co-design space as the exchange of lived and studied experience and reiterates that in Aboriginal contexts, co-design plays a vital role: it reminds service providers and governments that they should do things with, and not to, Aboriginal communities. Examples of co-design approaches in First Nations contexts are included, as are practical tips for how communities and researchers can co-design and co-produce evaluation and implementation. With an emphasis on mutual capacity building and knowledge weaving, tips include: ensuring that researchers are based in community and that improvements in the communities’ capacity to participate in co-design should form part of the evaluation. ‘Long time’ (planning and participating) is also central to co-design, as is the building of trust between Aboriginal people and Western academics, balancing perspectives of all community members and thoroughly understanding the context.

Hunt, J, 2013, *Engagement with Indigenous communities in key sectors, Resource sheet no.23 produced for the Closing the Gap Clearinghouse*

This resource sheet examines the evidence of what is working (or not) in approaches to engagement with Aboriginal and Torres Strait Islander communities in three key sectors. In relation to health programs, instances cited of where engagement worked best included: participatory processes with Aboriginal research assistants, focus groups, consultation and feedback processes with Aboriginal communities and health services; and drawing on the knowledge and ideas of Aboriginal Elders and Aboriginal health workers, developing them and consulting again until a program meets Aboriginal needs. Common lessons learnt about what works in engaging across sectors include:

- all parties must be committed to developing long-term sustainable relationships based on trust
- Indigenous people must be able to set their own time frames compatible with their own cultural protocols
- partnerships with Aboriginal people should operate within a framework of Aboriginal self-determination or Aboriginal decision making, with Indigenous-driven priorities
- power inequalities need to be addressed and where power inequality is recognised at the outset, genuine efforts must be made to share power
- staff must appreciate the historical context and have cultural knowledge
- there must be a willingness to share responsibility for shared objectives, e.g. to undertake joint planning, monitoring and evaluation.

Metro-Regional Intellectual Disability Network, *MRID CodesignKit*, produced with assistance of NSW Agency for Clinical Innovation

The MRID CodesignKit is one of a family of online toolkits (My MRID Toolkits) produced as an initiative of the MRID Network, which seeks to develop better health services for people with intellectual disability in regional and remote areas of NSW. It provides the tools and resources for anyone who wishes to develop and utilise co-design principles to develop better health services for people with intellectual disability. Practical information is included about how to best use focus groups, forums, social gatherings, questionnaires and surveys, clinic-based activities and communication platforms to employ a co-design approach, with specific attention given to the different needs of different people. It also contains a page relating to considerations when engaging culturally and linguistically diverse customers in co-design, with links to further resources.

Robinson, S, Fisher, K, Notara, D, Bullen, J, Johnson, K and Graham, A, 2016, *Telling Your Story: an evaluation of the Community Inclusion Initiative*, prepared for National Disability Services (NDS) by research team of Southern Cross University

NDS commissioned Southern Cross University to conduct an evaluation of the Community Inclusion Initiative (CII). The CII involved 11 disability day service organisations across Australia, each working with up to five participants with disability and their families to co-design new supports which increase their sense of community inclusion, over the course of a year. This report details outcomes for participants (including building personal well-being, social connectedness and increasing control in decision making) and reports on the effectiveness and sustainability of the project. In summary, some of the key learnings of relevance included: co-design was a good way to find out what was important to people; people with disability need a lot of help to embrace this new way of planning and it is not always easy to come up with big goals; and having competent and engaged staff and spreading the word about projects is important in building engagement.

Roy, A, McVilly, K and Crisp, B, 2018, 'Preparing for inclusive consultation, research and policy development: insights from the field of Deafblindness', *Journal of Social Inclusion*, vol. 9, no. 1.

This article was written in response to a perceived lack of guidance on good practice for engaging with people who are deafblind in the co-design of services. Based on research conducted, the authors found that to arrange events and consult with deafblind people in a spirit of co-design, professionals must have an awareness of the deafblind subculture and a deep understanding of the heterogeneous nature of deafblind communication. Specific adaptations regarding technologies, resources, orientation and mobility, communication and linguistic considerations would need to be made for deafblind people to be involved in co-design.

Summary

Key findings

Co-design and consumer engagement empower people affected by an issue to actively contribute to the development of a solution.¹¹⁵ Co-design is becoming more prevalent across organisations and sectors in policy development, research and in the development of programs and interventions.

Accordingly, there is an extensive range of different strategies, tools and methods for co-design and consumer engagement, which have been explored and tested in different contexts. A clear finding from this literature review is that there is no one perfect strategy or best practice model for engagement. Engagement strategies must be tailored to the situation and will differ based on the goals, participants, timeframes, resources and significance of the issues or changes.



The literature demonstrates that rather than a series of rigid steps, there is a clear set of principles that drive effective co-design and consumer engagement. As such, it is important that resources developed for aged care providers are flexible to suit the needs of different consumers and providers across different environments, instead of taking/providing a standardised approach.

By cataloguing the existing research and resources, this literature review provides the foundation for the development of further resources providing direction and motivation.

¹¹⁵ Blomkamp, E. 2018, 'The Promise of Co-Design for Public Policy', *Australian Journal of Public Administration*, vol. 77, pp. 729-743.

Three main conceptual approaches to consumer engagement were consistently referenced throughout the literature, around which various toolkits and resources have been developed:

Experience-based co-design (EBCD)

EBCD involves gathering experiences from consumers and staff through in-depth interviewing, observations and group discussions, identifying key ‘touch points’ and assigning positive or negative feelings. A short film is created from this and shown to consumers and staff to illustrate how consumers experience the service. Consumers and staff are then brought together to identify and implement activities to improve the service.

Action research

The Action Research Model is a method to facilitate change whereby the focus of each research project is determined by the researchers, who are also the primary consumers of the findings. It includes the consumer directing problem identification, experiential learning and the problem solving process.

VIPS

The ‘VIPS’ framework developed by Dawn Brooker sums up the elements of consumer-centred care for people with dementia as: Values, Individualised approach, the Perspective of the person living with dementia and Social environment. There are six indicators for each element providing concrete requirements for what constitute consumer-centred care.

These approaches will be explored in more detail through our consultation and drawn on to inform the final resources to ensure they are grounded in strong conceptual foundations.

There are a limited number of resources that are aged care-specific (particularly in Australia) and even fewer have been evaluated to determine their effectiveness. The resources developed through this project will fill a crucial resource gap by bringing together the existing models of consumer engagement and analysing their usefulness and success to date in the Australian aged care sector.

Next steps

This literature review will inform the development of resources for aged care providers and consumers regarding co-design and consumer engagement. It also provides useful background on some of the key principles underpinning these concepts and explains the benefits and challenges in applying them.

The literature review, including key findings and identified resources, will be further refined and expanded on over the course of this project, particularly as additional resources are identified through survey responses and consultation. As such, it is proposed that the literature review is not published at this stage but is instead published as part of a final set of resources for aged care providers and consumers.

Chapter 03 of the literature review directs those who are interested to additional better practice strategies and tools. Many of these practical tools will be built on as part of the final set of resources for providers and consumers, including to draw out the various forms of consumer engagement and co-design (e.g. holding workshops, patient shadowing, journey mapping, experience based surveys, empathy mapping, gathering patient stories, developing a stakeholder needs table, etc.).

Survey responses and further consultation will complement this research to create a comprehensive set of tools adapted to suit the Australian aged care context that can be applied across different care settings.

Bibliography

AccountAbility, 2005, *AA1000SE Stakeholder Engagement Standard*.

ACON, 2014, *LOVE Consultation Report: Service needs and preferences of Older Lesbian, Gay, Bisexual and Transgender People*, NSW.

ACON in partnership with NADA, 2017, *AOD LGBTIQ Inclusive Guidelines for Treatment Providers*, funded by Eastern and Central Sydney PHN.

Aged Care Quality and Safety Commission, Video resources from the Enhancing consumer engagement workshops conducted with COTA Queensland 2019: [Consumer engagement and the new aged care quality standards](#), [Why do we need to talk about consumer engagement?](#), [Engagement Mapping Tool demo video](#), [Need for Action](#)

Agency for Healthcare Research and Quality, 2015, *Partnering with Patients to improve quality, safety and the patient experience*, Department of Health and Human Services USA.

Alam, I. 2002, 'An exploratory investigation of user involvement in new service development' *Journal of the Academy of Marketing Science*, vol. 30, no. 3, pp. 250–261.

Alfred Hospital, [Patients Come First Strategy and Plan 2016-20](#).

Alfred Health, *Improving lives Quality Account 2015-16*.

Alzheimer's Australia, 2014, *Valuing People: A Literature Review to Support the Quality Dementia Support in the Community Project*, www.alzheimers.org.au

Alzheimer's Australia, 2008, *Perceptions of dementia in ethnic communities*, www.alzheimers.org.au.

Auckland District Health Board, 2019, [Health Service Co-design Toolkit](#).

Australian Aged Care Quality Agency, 2018, *Working together for quality aged care: A report on the outcomes of a series of aged care provider roundtables held in May 2018* July.

Australian Commission on Safety and Quality in Health Care, 2011, *Patient-centred care: Improving quality and safety through partnerships with patients and consumers*.

Australian Commission on Safety and Quality in Health Care, 2010, *Patient-Centred Care: Improving Quality and Safety by Focusing Care on Patients and Consumers – Discussion Paper*, September.

Australian Government Department of Health, February 2019, *Single set of quality standards, the Aged Care Quality Standards*.

Australian Government Department of Health, February 2019, *Actions to support Lesbian, Gay, Bisexual, Trans and Gender Diverse and Intersex Elders: A guide for consumers*.

- Australian Healthcare and Hospitals Association (AHHA) and Consumers Health Forum of Australia (CHF), 2017, *Experience Based Co-design: a toolkit for Australia*.
- Australian Institute for Primary Care and Ageing, 2013, *The Person-centred Care Assessment Tool (P-CAT)*, published by La Trobe University.
- Australian Institute of Aboriginal and Torres Strait Islander Studies, 2017, *Module 8: Engaging with Aboriginal and Torres Strait Islander Communities*
- Ballard, C et al, 2018, Impact of person-centred care training and person-centred activities on quality of life, agitation, and antipsychotic use in people with dementia living in nursing homes: A cluster-randomised controlled trial, *PLoS Med*, 6 February, 15(2).
- Benevolent Society, *Working with older Aboriginal and Torres Strait Islander people: Research to practice briefing 8*.
- Barrett, C and Malloy, 2018, *The Rainbow Makers: cultural safety and older LGBTI Australians*, produced for the National LGBTI Health Alliance.
- Bisognano, M. 2016, New Models for Elder Care: Three ways Norway inspired me, *Institute for Healthcare Improvement*, Tuesday 12 April.
- Blomkamp, E. 2018, The Promise of Co-Design for Public Policy, *Australian Journal of Public Administration*, vol. 77, pp. 729-743.
- Brown, H and Raines, T. 2013, *Co-production involving and led by older people: An Evidence and Practice Review*, National Development Team for inclusion.
- Brown, H. 2013, *A Framework for future action: guiding principles and practices for co-production with older people*, pp.22-25 in *Co-production involving and led by older people: An Evidence and Practice Review*, National Development Team for inclusion.
- Brooker, D and Latham, I, 2015, *Person-Centred Dementia Care, Second Edition: Making Services Better with the VIPS Framework Edition 2*, Jessica Kingsley Publishers.
- Buckland, D, Bashir, N, Moore, JE, Straus, S et al. 2017, *Canadian Task Force on Preventive Health Care patient engagement protocol*. Toronto: Li Ka Shing Institute, St. Michael's Hospital.
- Bunn, F, Goodman, C, Russell, B, Wilson, P, Manthorpe, J, Rait, G, Hodkinson, I and Durand, M, 2018, Supporting shared decision making for older people with multiple health and social care needs: a realist synthesis, *BMC Geriatrics*, vol. 18, no. 165.
- Buffel, T (ed), 2015, *Researching Age-Friendly Communities: Stories from older people as co-investigators*, The University of Manchester.
- Buffel, T. 2018, 'Social research and co-production with older people: Developing age-friendly communities', *Journal of Aging Studies*, vol. 44, pp.52-60.
- Cancer Australia and Cancer Voices Australia, 2011. National Framework for Consumer Involvement in Cancer Control. Cancer Australia, Canberra, ACT.
- Carrie Hayter Consulting, 2016, *Nothing about us without us – older citizens co-producing residential services – six key steps*, July.
- Central Coast Local Health District (NSW), 2014, Top 5 Toolkit Residential Aged Care Facilities: Integrating carer knowledge to improve care for residents with dementia, designed with the Clinical Excellence Commission as part of the Partnering with Patients program

- Centre for Policy on Ageing, September 2012, *How can the care experience of older people in care homes be improved: findings from five PANICOA studies*, [available at www.panicoa.org.uk/studies]
- Chenoweth, L, Stein-Parbury, J, Lapkin, S, Wang, A, Liu, Z and Williams, A, 2019, Effects of person-centered care at the organizational-level for people with dementia. A Systematic review, *PLoS One*, vol. 14, no. 2.
- Community West Inc, *Co-producing Aged Care Services with a Wellness Focus, [Part One: A Guide and Part Two: A Toolkit, Part Three: Tools & Activities]*, Step Forward – Together project funded by the Australian Government, September 2016.
- Coppola, M, Nurnberg, C, Poulimenos, D and Swanson, M, *Lessons physician groups can learn from the hospitality industry*, Huron Consulting
- Cornuz, J., Kuenzi, B. & Krones, T. 2011. Shared decision-making development in Switzerland: Room for improvement! *Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen*, vol. 105, no. 4, pp. 296-299.
- COTA Australia, 2014, *Co-creating Value: Lessons learned from Home Care Today's action research inspired co-production projects*, COTA.
- COTA Australia, *Consumer direction and dementia in the community*, PowerPoint presentation, Meaningful Living for Elders.
- COTA Australia, September 2014, *The voice of consumers in home care: a practical guide*, [accessed at www.homecaretoday.org.au].
- COTA, *Care Planning and Goal Setting (Norma's story case study)*.
- Coulter, A, Edwards, A, Elwyn, G & Thomson, R. 2011 'Implementing shared decision making in the UK', *Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen*, vol. 105, no. 4, pp. 300-304.
- Crawford, M J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N. & Tyrer, P. 2002 'Systematic review of involving patients in the planning and development of health care' *BMJ*, vol. 325, p. 1263.
- Curtis, L.C, Wells, S.M., Penney, D. J., Ghose, S. S., Mistler, L. A., Mahone, I. H., Delphin-Rittmon, M., Del Vecchio, P. & Lesko, S. 2010 'Pushing the envelope: shared decision making in mental health', *Psychiatric rehabilitation journal*, vol. 34, pp. 14-22.
- Dahlberg, T. 2018 *Engaging patients with culturally competent care*, Studer Group 15 October.
- Dementia Australia, 2019, *Family, friends and community*, Dementia Australia, April.
- Dementia Australia, 2018, *LGBTI and dementia*, Dementia Australia: funded by the Australian Government.
- Dementia Australia, 2018, *Younger onset dementia and the NDIS: A pathway to support*, Dementia Australia: funded by the Australian Government.
- Dementia Australia, Living well with dementia.
- Department of Health and Human Services, 2019, *Stakeholder Engagement and Public Participation Framework and Toolkit*, Melbourne.
- Dimopoulos-Bick, T, Dawda, P, Maher, L, Verma, R and Palmer, V, 2018, Experience based co-design: Tackling common challenges, *The Journal of Health Design*, Vol 3, No 1, p.89.

- Doughty, C. & Tse, S. 2011 'Can consumer-led mental health services be equally effective? An integrative review of CLMH services in high-income countries' *Community mental health journal*, vol. 47, pp. 252-66.
- Draper, R (Bolton Clarke), 2018, *Using a co-design approach to support aged care workers to understand and respond to the needs of transgender and gender diverse people.*
- Dreise, T & Mazurski, E, 2018, *Weaving Knowledges: Knowledge exchange, co-design and community-based participatory research and evaluation in Aboriginal communities, Literature Review, Case Study and Practical Tips*, Aboriginal Affairs New South Wales.
- Dubois, J. M., Bailey-Burch, B., Bustillos, D., Campbell, J., Cottler, L., Fisher, C. B., Hadley, W. B., Hoop, J. G., Roberts, L., Salter, E. K., Sieber, J. E. & Stevenson, R. D. 2011 'Ethical issues in mental health research: the case for community engagement', *Curr Opin Psychiatry*, vol. 24, pp. 208-14.
- Edvardsson D, 2015, 'Notes on person-centred care: What it is and what it is not', *Nordic Journal of Nursing Research*, vol. 35, no. 2, pp. 65-66.
- Elwyn G, Frosch, D and Kobrin S, 2016, Implementing shared decision-making: consider all the consequences, *Implementation Science*, vol. 11, pp. 114.
- Ennis, L., Rose, D., Callard, F., Denis, M. & Wykes, T. 2011. Rapid progress or lengthy process? electronic personal health records in mental health. *BMC Psychiatry*, 11.
- Entwistle, V and Watt, I, 2013, 'Treating Patients and Persons: A Capabilities Approach to Support Delivery of Person-Centered Care', *The American Journal of Bioethics*, vol. 13, no. 8, pp. 29-39.
- Equal Arts, *HenPower*.
- Federation of Ethnic Communities' Council of Australia, *Access and equity to Feedback and Complaints Mechanisms for Multicultural Communities*.
- Federation of Ethnic Communities' Council of Australia, 2015, *Review of Australian Research on Older People from Culturally and Linguistically Diverse Backgrounds*, funded by the Australian Government Department of Social Services.
- Filipe A, Renedo A and Marston C, 2017, 'The co-production of what? Knowledge, values and social relations in health care', *PLOS Biology*, vol. 15, no. 5.
- Fine, E., Reid, M. C., Shengelia, R. & Adelman, R. D. 2010. Directly observed patient-physician discussions in palliative and end-of-life care: A systematic review of the literature. *Journal of Palliative Medicine*, vol. 13, no. 5, pp. 595-603.
- Foroushani S, Travaglia J, Eikli M and Braithwaite J, 2012, *Consumer and community engagement: A review of the literature*, Australian Institute of Health Innovation, Agency for Clinical Innovation and University of NSW, Sydney.
- Fraser, J, 2013, *Little Book of Cultural Tips*, Diversicare, Brisbane.
- Fudge, N., Wolfe, C. D. A. & McKeivitt, C. 2011, 'Assessing the promise of user involvement in health service development: ethnographic study', *BMJ*, online.

- Giguere A, Adouni Lawani M, Fortier-Brochu E, Carmichael P, Legare F, Kroger E, Witteman H, Voyer P, Caron D and Rodrigez C, 2018, 'Tailoring and evaluating an intervention to improve shared decision-making among seniors with dementia, their caregivers, and healthcare providers: study protocol for a randomized controlled trial', *BMC Open Access: Trials*, vol. 19, p. 332.
- Gill L, Bradley S, Cameron I and Ratcliffe J, 2018, 'How do clients in Australia experience Consumer Directed Care?', *BMC Geriatrics*, vol. 8, no. 148.
- Global Centre for Modern Ageing, 10 May 2019, *Co-designing Aged Care in Strathalbyn: Outcomes Report*.
- Grant-Nierman M, May 2016, *Partnering with Patients to Improve Quality, Safety and the Patient Experience*, Agency for Healthcare Research and Quality.
- Goeman, D, 2016, 'Partnering with consumers to develop a Vietnamese Dementia Talking Book' in *Improving the healthy ageing experience of older CALD Australians: Integrating research, policy and practice*, Australian Mosaic: the magazine of the Federation of Ethnic Communities' Councils of Australia
- Goodman C, Davies S, Gordon A, Denning T, Gage H, Meyer J, Schneider J, Bell B, Jordan J, Martin F, Iliffe S, Bowman C, Gladman J, Victor C, Mayrhoder A, Handley M and Zubair M, 2017, 'Optimal NHS service delivery to care homes: a realist evaluation of the features and mechanisms that support effective working for the continuing care of older people in residential settings', *Health Services and Delivery Research*, vol. 5, no. 29.
- Goodrich J, 2018, 'Why experience-based co-design improves the patient experience (editorial)', *The Journal of Health Design*, vol. 3, no.1, pp.84-85.
- Goodwin C, 2016, 'Person-Centered Care: A Definition and Essential Elements', *Journal of the American Geriatrics Society*, vol 64, pp. 15-18.
- Gustavsson, S and Andersson, T, 2017, Patient involvement 2.0: Experience-based co-design supported by action research, *SAGE journals*, 7 August
- Hayter, C, 2017, Small steps, big changes: empowerment and inclusiveness needed for older Australians, *Aged Care Insite*, 8 March
- The Health Foundation, March 2014, *Helping measure person-centred care: A review of evidence about commonly used approaches and tools used to help measure person-centred care*, excel spreadsheet.
- Health Innovation Network South London, *What is person-centred care and why is it important?*
- Helping Hand, 2012, *Consumer and Engagement Framework*.
- Hunt, J, 2013, *Engagement with Indigenous communities in key sectors*, Resource sheet no.23 produced for the Closing the Gap Clearinghouse
- InnovAgeing, 2019, *Whiddon introduces MyLife and ASCOT in care planning*.
- Integrated Resource Framework (IRF) Co-production Learning Template*, 2008, developed as part of the Shifting the Balance of Care Delivery Group project.
- The International Association for Public Participation Australasia, 2007, *IAP2 Spectrum of Public Participation*.

- Janamian T, Crossland L and Wells L, 2016, On the road to value co-creation in health care: the role of consumers in defining the destination, planning the journey and sharing the drive, *MJA Elsevier* 204(7), 18 April
- Jenkins, K, Eade, R, Bartsch, C and Yang, E (2017) *Consumer Directed Care Reform: Consumer Engagement Toolkit*, project undertaken as part of *Engaging Young Leaders on Aged Care & Community Boards*
- Jordan M, Rukas G, 2017, *Emerging Ageing: co-designing responses to positive ageing for new and emergent migrant communities*, Project Report, Ethnic Communities' Council of Victoria and Per Capita
- Joseph-Williams N, Lloyd A, Edwards A, Stobbart L, Tomson D et al, 2017, Implementing shared decision making in the NHS: lessons from the MAGIC programme, *BMJ Publishing Group*, 357: j1744
- Kennedy A, Reeves D, Bower P, et al, 2007, 'The effectiveness and cost effectiveness of a national lay-led self care support programme for patients with long-term conditions: a pragmatic randomised controlled trial', *Journal of Epidemiology & Community Health*, vol. 61, pp. 254-261.
- Kim S K, Park M, 2017, Effectiveness of person-centred care on people with dementia: a systemic review and meta-analysis, *Clinical Interventions in Ageing*, vol. 12, pp. 381-397
- KPMG Global Healthcare, 2014, *Creating new value with patients, carers and communities*.
- Krebs, V. & Holley, J. 2006, 'Building smart communities through network weaving', *Appalachian Center for Economic Networks*.
- Leading Aged Care Services (LASA), 2018, *Fusion: the voice of aged care, newsletter*.
- Legare, F., Ratte, S., Stacey, D., Kryworuchko, J., Gravel, K., Graham, I. D. & Turcotte, S. 2011 'Interventions for improving the adoption of shared decision making by healthcare professionals [Systematic Review]'. *Cochrane Database of Systematic Reviews*.
- Leslie M, Khayat-zadeh-Mahani A, MacKean G, 2019, Recruitment of caregivers into health services research: lessons from a user-centred design study, *Research Involvement and Engagement: BMC Open Access*, vol. 5, no. 17.
- Life Without Barriers, *Engaging with Aboriginal and Torres Strait Islander people: The Life Without Barriers Practice Approach*.
- Lindeman M A, et. al. 2003, Changing Practice in Residential Aged Care Using Participatory Methods, *Education for Health*, vol. 16, no. 1, pp. 22-31
- Lovell K, Bee O, Brooks H, Cahoon P, Callaghan P, Carter L A, et al, 2018 Embedding shared decision-making in the care of patients with severe and enduring mental health problems: The EQUIP pragmatic cluster randomised trial, *PLOS One*, vol. 13, no. 8.
- Lyttle, D. J. & Ryan, A. 2010, 'Factors influencing older patients' participation in care: a review of the literature' *International journal of older people nursing*, vol. 5, pp. 274-82.
- Maher, L, Hayward, B, Hayward, P and Walsh, C, 2017, Increasing patient engagement in healthcare service design: a qualitative evaluation of a co-design programme in New Zealand, *Patient Experience Journal*, vol 4, no. 1, article 4.
- McCormack, B, Dewing, J and McCance, T, 2011, Developing Person-Centred Care: Addressing contextual challenges through practice development, *The Online Journal of Issues in Nursing*, vol. 16, no. 2.

- Menon D, Stafinski T, 2011 'Role of patient and public participation in health technology assessment and coverage decisions', *Expert Rev Pharmacoecon Outcomes Res.*, vol. 11, no. 1, pp. 75-89.
- Metro-Regional Intellectual Disability Network, *MRID CodesignKit*, produced with assistance of NSW Agency for Clinical Innovation
- Moyez Jiwa (ed), 2018, 'Patients as co-designers to improve the quality of care', *The Journal of Health Design*, vol 3, no 1.
- Myhomelife Toolkit: Conversations for Quality Improvement.
- Mulvale, G, Moll, S, Miatello, A, Robert, G, Larkin, M, Palmer, V, Powell, A and Gabel, C, 2018, 'Co-designing public services with vulnerable and disadvantaged populations: Insights from an international collaboration', *Service Design Proof of Concept Politecnico*, Milan.
- Narino, S 27 November 2018, *Is Co-Design the key to humanizing health care?*, Institute for Healthcare Improvement.
- National Institute for Health and Care Excellence, 2018, *Dementia: assessment, management and support for people living with dementia and their carers*, NICE guideline [NG 97], London.
- National Institute for Health and Care Excellence, 2015, *Home care: delivering personal care and practical support to older people living in their own homes*, NICE guideline [NG 21], London.
- NESTA, *People powered health co-production catalogue*, London.
- NHMRC 2006, *Guide to effective participation of consumers and communities in developing and disseminating health information*, Canberra, Australian Government.
- NHS England, 2015, *Personalised care and support planning handbook: the journey to person-centred care*.
- NSW Agency for Clinical Innovation, *Experience-Based Co-design Toolkit*.
- NSW Agency for Clinical Innovation, *Consumer engagement Agency for Clinical Innovation (ACI) Giving a voice to stakeholder perspectives*, summary of report produced by Australian Institute of Health Innovation (AIHI).
- Nusem, E, Defries, A and Wrigley, C 2015, Applying design-led innovation in a not-for-profit aged care provider to create shared value, in Muratovski, G (ed) *Design for Business*, University of Chicago Press/Intellect Books, Bristol, pp.172-193.
- O'Brien N, Heaven B, Teal G, Evans E, Cleland C, Moffatt S, Sniehotta F, White M, Mathers J, Moynihan P, 2016, 'Integrating Evidence from Systematic Review, Qualitative Research and expert knowledge using co-design techniques to develop a web-based intervention for people in the retirement transition', *Journal of Medical Internet Research*, vol. 18, no. 8.
- O'Connor, A., Stacey, D., Bennett, C. L., Barry, M. J., Col, N. F., Eden, K. B., Holmesrovner, M., Llewellynthomas, H., Lyddiatt, A., Legare, F. & Thomson, R. 2011. Decision aids for people facing health treatment or screening decisions [Systematic Review]. *Cochrane Database of Systematic Reviews*, vol. 10, no. 10.
- Office for the Ageing, *Better Together: A Practical Guide to Effective Engagement with Older People*, Government of South Australia
- Owen T and NCHRDF (ed), 2006, *My Home Life: Quality of life in care homes*, Help the Aged in partnership with the National Care Forum and the National Care Homes Research and Development Forum, London.

- Petriwskyj, A, 2017, *Client Engagement Toolkit: A Resource for Aged Care Staff*, The University of Queensland
- Point of Care Foundation, *Experience-based co-design toolkit*.
- Rahman, M, McDonald, E, Edvardsson, K, Pascoe, L, Lood, Q, Jokwiro, Y and Edvardsson, D, 2018, 'Psychometric analyses of the person-centred climate questionnaire-Family (PCQ-F) in Australia, Norway and Sweden', *Innovation in Aging*, vol. 2, no. 11, pp.127-128
- Realpe A and Wallace I, 2010, *What is co-production?*, The Health Foundation, London.
- Reid, P, 2015, Why we need a co-design approach to transitional care, *Hospital and Healthcare*
- Robinson, S, Fisher, K, Notara, D, Bullen, J, Johnson, K and Graham, A, 2016, Telling Your Story: an evaluation of the Community Inclusion Initiative, prepared for National Disability Services (NDS) by research team of Southern Cross University.
- Rodgers, P, 2016, Co-designing with people living with dementia, *International Journal of CoCreation in Design and the Arts*, vol 14, no. 3, pp. 188-202
- Rosvik, J, 2013, 'Development, evaluation and the effects of the VIPS practice model for the person-centred care of patients with dementia. An intervention study in Norwegian nursing homes', *Akademia Publishing: Series of dissertations submitted to the Faculty of Medicine*, University of Oslo no. 1808.
- Roy, A, McVilly, K and Crisp, B, 2018, 'Preparing for inclusive consultation, research and policy development: insights from the field of Deafblindness', *Journal of Social Inclusion*, vol. 9, no. 1.
- Royal Commission into the Aged Care Quality and Safety Commission, May 2019, Statement of Professor Henry Brodaty.
- Royal Commission into the Aged Care Quality and Safety Commission, Statement of Merle Valma Mitchell AM, 27 April 2019
- SA Health, 2013, *Guide for Engaging with Consumers and the Community: a practical toolkit to assist health care services to implement A Framework for Active Partnership with Consumers and the Community*
- Sanders B and Stappers P, 2008, 'Co-creation and the new landscapes of design', *Co-Design*, vol. 4, no. 1, pp. 5-18.
- Sanders, E 'From User-Centred to Participatory Design Approaches', 2002 in Frascara, J (ed) *Design and the social science: Making connections*, pp.1-8, London, Taylor and Francis
- Santana M, Manalili K, Jolley R, Zelinsky S, Quan H and Lu M, 2018, How to practise person-centred care: A conceptual framework, *Health Expectations: an International Journal of Public Participation in Health Care and Health Policy*, 21(2), April, pp.429-440
- Shifting the centre of gravity*, January 2019, *Making place based person-centred health and care a reality*, podcast 8.
- Sleeswijk Visser F, Stappers PJ, Van der Lugt R, Sanders EBN, 2005, 'Context mapping: experiences from practice' *CoDesign*, vol. 1, pp. 119-49.
- Social Care Institute for Excellence, 2013, *Co-production in social care: What it is and how to do it*, London.
- Stacpoole, M, Thompsell, A and Hockley, J, 2016, *Toolkit for implementing the Namaste Care programme for people with advanced dementia living in care homes*, St Christopher's, London.

- Steen, M, Manschot, M and De Koning, N, 2011, 'Benefits of Co-design in Service Design Projects', *International Journal of Design*, vol. 5, no. 2, pp. 53-59.
- Tan, L and Szebeko, D, 2009, Co-designing for dementia: The Alzheimer 100 project, *Australasian Medical Journal*, 1, 12, pp.185-189
- Tay, F, Thompson, C, Chiang Nieh, C, Ming Nieh, C, Mien Koh, H, Cheen Tan, J, and Yap, P, 2018, 'Person-centred care for older people with dementia in the acute hospital', *Alzheimer's & Dementia: Translational Research & Clinical Interventions* 4, pp. 19-27
- Thabrew H, Fleming T, Hetrick S and Merry S 2018 'Co-design of eHealth Interventions With Children and Young People' *Front. Psychiatry*, vol. 9, p. 481.
- Think local act personal, May 2019, *Podcast: Co-production and the art of conversation*.
- Think local act personal, *Personalised care and support planning tool*, <https://www.thinklocalactpersonal.org.uk/personalised-care-and-support-planning-tool/>
- Victorian Agency for Health Innovation and Safer Care Victoria, *Online resources*.
- Victorian Department of Health, *Service guideline on gender sensitivity and safety – Literature review*.
- Victorian Government Department of Health, 2010, *Supporting people in care relationships*, Melbourne.
- University of Gothenburg, GPCC – Centre for person-centred care, *The PCC Game app – learn by playing*.
- Warr, D, Dickinson, H, Olney, S, Hargrave, J, Karanikolas, A, Kasidis, V, Katsikis, G, Ozge, J, Peters, D, Wheeler, J and Wilcox, M, 2017, *Choice, control and the NDIS: Service users' perspectives on having choice and control in the new National Disability Insurance Scheme*, University of Melbourne, Melbourne.
- Western Australian Department of Health, 2017, *You Matter: A Guideline to support engagement with consumers, carers, communities and clinicians in health*, Quality Improvement and Change Management Unit, Perth.
- Wherton, J, Sugarhood, P, Procter, R, Hinder, S and Greenhalgh, T, 2015, 'Co-production in practice: how people with assisted living needs can help design and evolve technologies and services', *Implementation Science*, 10: 75
- World Health Organization and UNICEF, September 1978, *Declaration of Alma-Ata*. International Conference on Primary Health Care, Alma-Ata USSR.
- Wright, R et al (2018) Using experience-based co-design with older patients, their families and staff to improve palliative care experiences in the Emergency Department: A reflective critique on the process and outcomes, *International Journal of Nursing Studies*, vol. 68, pp. 83-94.



Phone

1800 951 822



Web

agedcarequality.gov.au



Write

Aged Care Quality and Safety Commission
GPO Box 9819, In Your Capital City