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Title Consumer co-creation in health: innovating in Primary Health Networks

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Policy issue

While healthcare consumers continue to be involved as active participants in managing their own health, the focus is now moving to include consumers in value creation in health care planning and delivery. As the health system moves toward a devolved model of care, the need to focus on consumer's needs is increasingly important at both a policy and practice level. The growing body of literature on health value co-creation and its benefits in the health sector shows that value can be co-created for the individual consumer, clinical practices, health care organisations, and governments.

Primary Health Networks (PHNs), Australia's newest form of regionally based primary care organisation, have both contractual obligations as well as community expectations that they will systematically incorporate consumer perspectives into their planning and decision making. Over time, they may jointly commission services with Local Hospital Networks (LHNs).

The evidence base regarding the benefits and challenges for healthcare involvement in value co-creation has arisen from a broad range of fields and is well established internationally. However, to date there has been minimal research into how this can be applied to the Australian context. Instead, practitioners and policy makers are applying what has been found in the UK and other countries directly to the Australian context. As the following brief shows, this has been done successfully in a number of instances and will continue to evolve, particularly in the primary health and integrated care sectors as PHNs mature in their role as commissioners of health services.

The Consumers Health Forum of Australia (CHF) and the Australian Healthcare and Hospitals Association (AHHA) held a workshop in August 2016 entitled: "Taking consumer engagement to the next level: How can PHNs and LHNs involve healthcare consumers in co-creation to improve health care?" The workshop outlined the theory and evidence behind co-creation and highlighted series of examples of where co-creation is being used in the Australian context. Speakers included managers and directors of PHNs, state government representatives, researchers, clinicians alongside consumer advocates.

This brief synthesises examples from existing theory and practice to provide recommendations about how to best involve healthcare consumers throughout their work.

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What does the evidence say?

Current state of patient centred care

Consumer engagement, health value co-creation and patient centred health care are increasingly well-recognised concepts in the health sector, both in Australia and internationally. A range of definitions and approaches are used in the literature (1–3). This brief defines value co-creation as ‘a process whereby all stakeholders jointly contribute to the ideation, planning, implementation and evaluation of new services and systems as a possible means to optimise outcomes’.

Value co-creation is relevant to the Australian health system because of the increasing need to improve care in the context of our complex funding framework and the broad geographic and demographic range that exists across our nation (1). Policy makers perceive this to be a tool to address these challenges, as shown by the way that all states and territories in Australia have policies and strategic plans for how to implement patient centred health care. Despite this acknowledgement however, what constitutes best and most effective practice in this area remains unclear (1). As new entities, Primary Health Networks have been structured with this in mind. Each PHN has a Community Advisory Committee to provide healthcare consumer input into decisions, innovations and investments and ensure that these are patient-centred, cost effective and locally relevant. Some have adopted additional strategies such as patient panels and community portals.

Benefits that arise from using co-creation

Value co-creation has been shown to benefit the health system on a range of levels. The benefits to individual users of the health system include: an increased level of trust and confidence in services (1,3); provision of services that offer personalised care and value for money (4); recognition of their right to equitable access to health care (1) and increased rates of health literacy (2).

The benefits to health services and practitioners include: an increased perception of public value (1); robust and enduring partnerships (5); and compliance with treatment regimens (3).

The benefits to the health system at a macro level include: efficiency gains and consequently a reduction in overall health care costs (1–3); outcomes that consumers value (5); improved health outcomes (3); and improved patient satisfaction (3).

Challenges and barriers to the use of co-creation

Involving consumers is not without challenges, however. It has been suggested that too much patient autonomy may lead to a reduction in outcomes through poor

intervention choices and that customisation may make standardisation across patients challenging.

This tension highlights one of the key challenges of involving consumers—where does the responsibility for treatment decisions ultimately fall? The current literature suggests that the burden of responsibility and accountability must remain on professionals, not patients (7), however this is an ongoing area of tension.

In addition to this challenge, a range of barriers exist for policy makers and practitioners involving consumers throughout their work. Three macro-level barriers have been identified in the literature:

- The division of services between sectors and organisations (6);
- Health care professionals can be resistant to co-production and engaging people (3,7); and
- The fee for service model which has been shown to inhibit collaboration between providers (6).

Additionally, four meso-level barriers have been identified:

- Lack of dialogue between stakeholder groups;
- Access to consumer groups and opinions;
- Varying understanding of the risks and benefits of involving healthcare consumers; and
- Lack of transparency in the broader health care system (3).

These barriers and challenges, many of which have not been conclusively resolved, show that the process of how consumers are involved in value co-creation remains an evolving area. The following sections document some of the way that consumers have been involved to date, followed by specific examples of how this has been implemented in Australia.

Healthcare consumers involved in value co-creation

Ways in which consumers can be involved

Strategic policy

For value-co creation to be effective it must be enshrined at a strategic policy level (1,8) such as accreditation practices (6). This can be achieved in a range of ways, such as having patients participate in policy, health technology assessment and programme development (5,8), through identifying and supporting influential champions (5) and through recognising what value is to the particular stakeholder groups (5).

User centered design

Involving consumers in the development and design of services, a technique commonly referred to as user centred design, is one of the major ways in which consumers have been involved in healthcare (1). User centred design can be achieved through the use of a range of techniques, such as creating purpose designed methods of engagement (5) and prioritising individualisation and customisation in design processes (9).

Consumer activation and leadership

Increasing the understanding and consequent capabilities of all parties in the health workforce to engage in patient centred health care is a key way in which consumers can be more effectively engaged in their own care (7). This may be achieved in a range of ways, such as including consumer-centred care as a part of the training of professionals (6,8) and providing ongoing training for professionals in how they can best communicate with their patients regarding their care (1). Additionally, consumers can be involved through training and supporting patient leaders to advocate on behalf of the wider patient population (6). Finally, they can also be involved through the use of personal health or social care budgets, which have been shown to increase self-determination, quality of life and social wellbeing as well as being cost-effective (2,8).

Research

Being involved in research as part of care and treatment has been shown to bring a wide range of benefits to consumers (8). These benefits include improved access to services, increased monitoring, being paid, and a perception that health consumers are valued (2). At an organisational level, involvement in research has been shown to have a positive impact on health care performance (2).

Measuring consumer experience

Measuring and publishing the results of consumer experience surveys has been shown to increase the standard of care that practitioners provide (10) and not acting on feedback has been shown to have a damaging impact (2). Higher patient satisfaction is associated with improved guideline adherence and lower patient mortality rates (11,12). However, a review of how and when patient experience data is collected has shown that the quality and regularity of the collection of this data varies widely (13).

Practitioners assisting patients to engage with their healthcare

Ways in which practitioners can increase healthcare consumers' abilities to engage with and support their own care has been shown to lead to a range of improvements, such as increased levels of health literacy, particularly around rights, treatment options and costs (1,6). This section details a range of evidence-based ways that practitioners can do this.

Decision aids

Decision aids are one way in which information can be effectively communicated to patients and have been shown to increase adherence to treatment regimes, help patients make more conservative treatment decisions and reduce the rates of elective surgery (14). However, the production of these aids is expensive, additional time is needed to ensure patients understand them and their effectiveness is dependent on patients using them regularly (14).

Framing interactions as two-way conversations

A substantial body of literature exists regarding the instrumental role of patient-provider interactions in the creation of positive health outcomes. Interactions can be made to be more consumer centred in a range of ways, such as:

- Reframing the interaction as a conversation instead of merely a one way exchange of information about how symptoms should be treated (9);
- Taking consumer's capabilities and levels of motivations into account when discussing treatment plans and options (2);
- Supporting consumers in accessing services in their choice of mediums, e.g. telehealth and the use of technology-based information systems (6,8); and
- Displaying transparency in interactions, such as through clear disclosure of costs and explanations of processes (9).

Emerging practices

Existing and emerging practice involving health consumers

Australia is in the enviable position of being able to learn from other countries, including New Zealand and the United Kingdom. However, our geographical diversity presents its own set of unique challenges, which must be addressed to ensure that our health care system places consumers at the very centre.

Each health service needs to be able to tailor their approach to their unique situation, both in terms of geographical location and type of health sector within our complex health system. To help facilitate this we have compiled a range of best practice examples from Australia to illustrate some ways in which consumer centred care can, and has, been implemented at both a policy and practice level. The following examples, while not exhaustive, show that there is no one size fits all approach to involving healthcare consumers in local health networks.

Accreditation standards: ACSQH's Standard 2

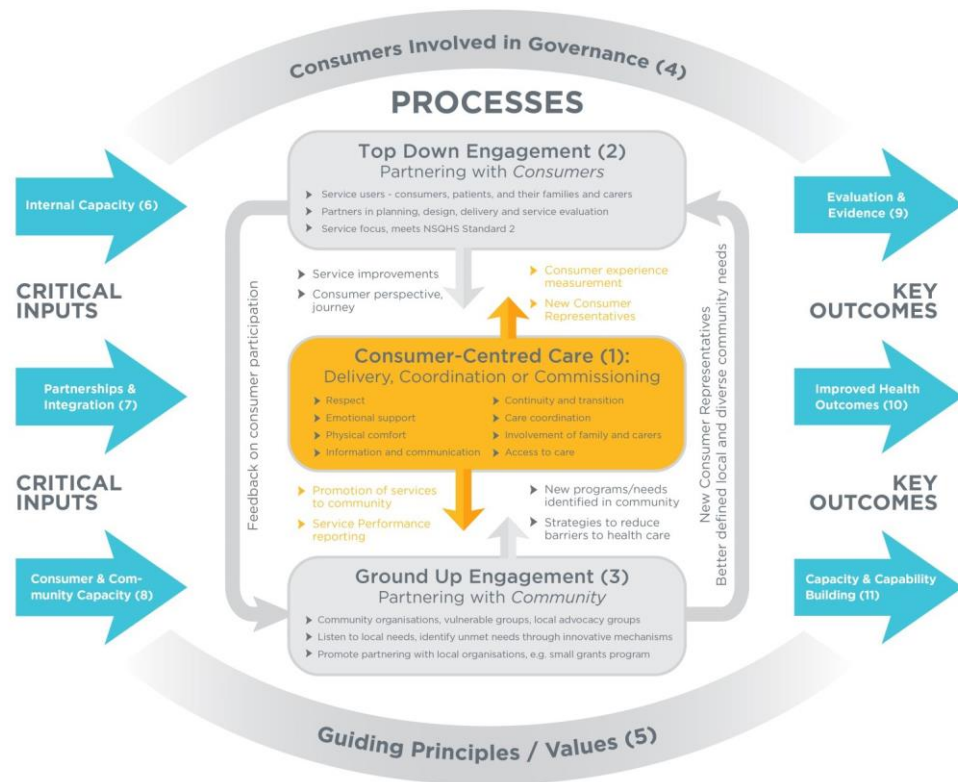
The Australian Commission on Safety and Quality in Healthcare's Standard 2 requires all hospitals, day procedure services, the majority of public dental services and some private services to actively work with healthcare consumers to ensure that health information, systems and services meet their needs. This Standard and the considerable related materials provide national level guidance for creating consumer-centred policies and practices (1).

Commonwealth guidelines: Community Advisory Committees

The Commonwealth Government has made Community Advisory Committees a requirement for Primary Health Networks. These committees, which have been implemented in various ways, are to report to PHN boards and collaborate with clinical councils; ensure local accountability and relevance of PHN activities; promote patient centred decision making and needs identification; reflect the diversity and needs of the local population and align with clinical councils, determined by PHNs, based on regional needs.

A comprehensive model for involvement: WentWest and Health Care Consumers NSW

WentWest, the PHN for Western Sydney and Health Consumers NSW conducted a joint consumer engagement project over the period of 2013–15 (16). Their model shown in the diagram below, places consumer-centred care at the heart of the PHN through the use of a top down—ground up engagement process. Their ‘top down’ approach involves engagement being initiated by the organisation. This engagement is focused on services already planned or being delivered for known health needs with existing services. This is complemented by a ‘ground up’ approach, which takes place with communities to explore, understand and determine how to best meet their diverse health care needs. This type of engagement identifies gaps in services, access issues and other unmet needs. These approaches are supplemented by a range of additional processes which help guide organisations in their approach to involving health consumers in improving care.



Consumer and Community Engagement Model: WentWest Health Consumers NSW Joint Consumer Engagement Project

Tackling the challenge of geographical diversity

Western Australia Primary Health Alliance (WAPHA) is made up of three Primary Health Networks. Their community engagement strategy varies between the two metropolitan PHNs (Perth North and Perth South) and the third rural and regional PHN (Country WA). Perth North and South PHNs have community engagement committees which are sub committees of their main governing councils. By contrast Country WA, which covers the largest geographical area of any PHN in Australia, employs community working groups in each of the regions of the PHN.

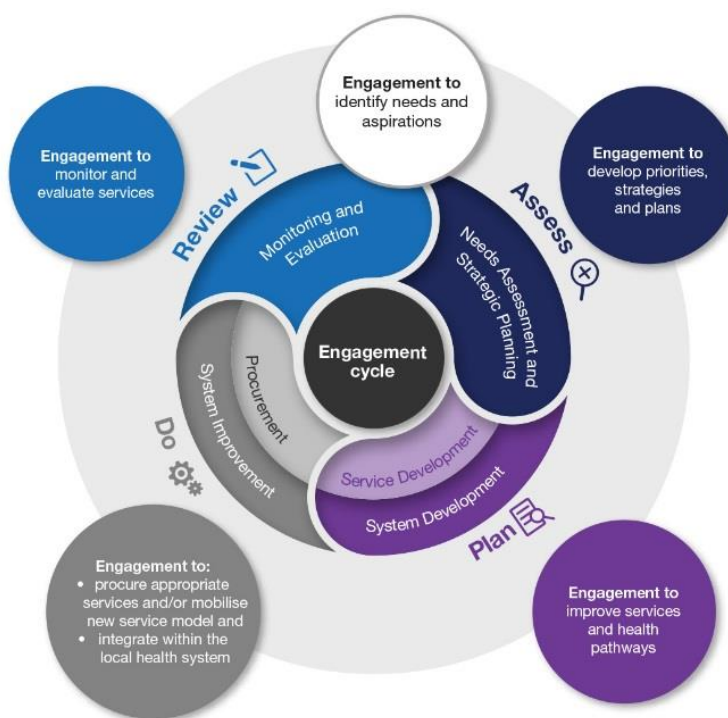
These are employed on an as needs basis as well as working collaboratively with existing groups and networks including the District Health Advisory Councils and the Aboriginal Health Regional Planning Forums. The membership of all of these formally established groups involve community, carer and consumer representatives.

Representation at all levels: Capital Health Network

Capital Health Network (CHN), the Australian Capital Territory’s PHN, provides a clear example of how the structures suggested by the Commonwealth can be put into practice. Firstly, their membership includes consumer and carer representative organisations. Individual consumers and carers can be affiliate members and receive CHN communications. Their board has a consumer director and is supported by their Community Advisory Council—a standing committee which provides consumer focused and community relevant advice to the board. This committee comprises community, consumer and carer representation, advocates and opinion leaders. Finally, consumer and carer representation is secured on any committees, advisory groups, program steering groups and *ad-hoc working groups as needed*.

Capital Health Network Engagement Model

Consumer representation both informs the development of engagement strategies at each stage of the commissioning cycle, provides consumer leadership in engagement activity and ensures the results inform corporate decision making processes. This approach reinforces a balanced approach to commissioning activities with an emphasis on person-centred health care and community relevance.



Capital Health Network Engagement Model

The North Brisbane PHN employed a group of consumer and carer evaluators to evaluate their implementation of the national Partners in Recovery program, and in doing so, provides one of the most extensive examples of how healthcare consumers have been involved in a service to date. Consumer evaluators were selected through an application process and were then trained, with significant time being devoted to ensuring they felt like they were part of the team and felt equipped to do what was required of them. The primary outcome of the project was the evaluation of the program and was considered a success. The evaluation team identified a number of learning points, including:

- The amount of time and flexibility which is needed to involve consumers cannot be underestimate;
- There is a significant potential for the consumers involved to be triggered, or re-traumatised, through their involvement. Care needs to be taken to ensure this doesn't happen, as in some cases consumers were not able to undertake the activities they were employed to do; and
- Employing consumers had a flow on, capacity-building effect into the wider sector.

Capturing the everyday experience: Patient Reported Outcomes Measures (PROMs) and Patient Reported Experience Measures (PREMs)

Patient reported outcome and experience measures enable services and policy makers to easily and effectively capture and understand consumer's experiences of services. A range of measures exist which can be used 'off the shelf' or which can be tailored to specific circumstances. They provide accessible, consistent and transparent information which is relevant and meaningful to clinicians and consumers.

Sharing voices effectively: Real People Real Data

Systematically collected and analysed healthcare consumer narratives have been shown to be an effective way of providing whole of life and system insights to policy makers and practitioners. Real People Real Data is one way in which these stories can be collected and conveyed. The toolkit provides organisations with a simple framework through which to capture these narratives, analyse the stages of life journey or the health process the consumers have been through and convey this information in formats that can assist program and service development and improvement.

Recommendations

A range of recommendations arising out of the literature and case studies from the workshop were identified and are presented here.

Capacity and knowledge building

Development of an experience based co-design resource kit or training program

No specific resource kit or training program currently exists to assist PHNs in involving consumers in their role as commissioning agents. Current resources for other services should be adapted to create a specific, easy to use and understand resource for this purpose.

Adaptation of the 'Co-creating Health' initiative

In order to embed self-management support within mainstream health services the UK's National Health Service has developed and evaluated the 'Co-creating Health' initiative. This initiative showed that supported self-management can result in a reduction in healthcare consumer's use of services and rates of non-attendance.

We recommend that the Co-creating Health initiative be adapted and trialled in Australia through a pilot and subsequent evaluation.

Investment in consumer leadership

Assisting healthcare consumers to not just participate in, but to lead the health system is a key mechanism through which value can be co-created. Currently no national level program exists to equip them to do this, however. **We recommend that consideration is given to developing or adapting a national consumer health leadership program.** This could be designed for regional or state delivery leveraging off existing training partnerships.

Increased measurement and reporting

Systematic reporting of consumer centered policies and practices.

The current system of developing consumer centred practice is fractured, which may lead to the duplication of efforts across Australia. A central, national level, clearinghouse or database of these efforts would reduce this.

National level database of patient experiences

Currently no national level database exists of patient experiences across the health system. While attempts have been made to do this at local levels, collecting this data at a higher level would enable policy makers and practitioners to compare and contrast the effectiveness of endeavours. Both this and the above database could be collated and reported against by the Australian Institute of Health and Welfare as part of their regular reporting on the health system.

Key outcome measures

PHNs and LHNs need to work together to meet consumers expectations of the health system at a whole. While from a policy and funding perspective the organisations are different, consumers are unlikely to discriminate between them. Because of this, a coordinated approach is needed to ensure that the needs of the community are being met.

Summary

Leadership and change management

Moving toward a consumer-centred health system is not a simple task, and doing so effectively will require more attention being paid to change management than is currently being allocated. There is a need to move away from deciding, announcing and defending our practices and toward effectively managing this change by focusing efforts on: workforce training, professional colleges, regional bodies charged with commissioning services (PHNs) and the design and delivery of services (LHNs).

Executive level leadership

A common thread presented in the exemplars was a high level of engagement and leadership from the executive level of organisations. Boards and the executive

leadership of health networks need to be prepared to champion consumer centred care and provide adequate space and time for their organisations to genuinely engage consumers.

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