

Collaborative Pairs Australia National Demonstration Trial



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Health Economics



Curtin University

Review of existing evidence

Prepared by: **Lauren Spark¹, Suzanne Robinson¹ and Helen Dickinson²**

¹ Health Systems and Health Economics, School of Public Health, Curtin University

² Public Service Research Group, School of Business, University of New South Wales, Canberra

Collaborative Pairs Review

Executive summary	i
Introduction	ii
Review methods	iii
Part 1. Consumer participation and consumer leadership: A review of the literature	01
Consumer participation at the individual and health system level	01
Distinguishing between micro and macro levels of consumer participation	01
Moving beyond consumer participation to consumer leadership	01
Challenges for consumer participation at the individual and organisational level	02
Challenges for consumers	02
Challenges for organisations	02
Elements of collaboration needed to influence system change	03
Individual-level elements	03
Develop leadership skills to form relationships	03
Commit to a shared vision and demonstrate shared leadership	04
Engage in a shared learning approach and growth mindset	04
Organizational-level elements	04
Recruit, train and support appropriate consumer workforce	04
Provide a positive organizational environment	05
Normalise organizational collaborative practices and processes	05
Part 2: Collaborative Pairs Review	06
The English health context	06
English health system reform	06
Need for efficient, coordinated and sustainable health systems	06
Need to improve quality of care	06
Need for local leaders working in collaboration	06
Need to acknowledge patient preferences to be involved in shared decision-making	07
Summary	07
Collaborative Pairs Program review	07
Program aim and objectives	07
Program content and methodology	07
Program implementation in England	08
Collaborative Pairs participants	08
Program outcomes	08
Anticipated benefits for participants	08
Broader benefits of consumer participation	08
Program impact	09
Anticipated program impact	09
Quantifying outcomes of the Collaborative Pairs program	09
Bringing this back to Australia	10
Application of Collaborative Pairs program to the Australian context	10
Summary	11
References	12
Appendix One	13

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Executive summary

The Consumers Health Forum of Australia (CHF) in collaboration with the King's Fund (UK) and four Primary Health Networks (PHNs) in NSW and Victoria have undertaken an Australian national demonstration trial of the King's Fund Collaborative Pairs (CP) program. The Collaborative Pairs program is a leadership development program that brings together a consumer, patient or community leader to work together in pairs with a service provider, clinician or manager to develop new ways of working together.

As background to this demonstration trial, this report reports a scoping review of the extant knowledge to identify practical and relevant information related to the Collaborative Pairs context, program, methodology and outcomes.

This review:

- Explores the English health context and rationale for program developments in this area;
- Examines information relating to all aspects of the CP program, including content, methodology and implementation;
- Explores the evidence around CP program effectiveness and learnings from England, including impacts of the program on practice (service and project outcomes, as well as actual and potential impacts on the health system reform more broadly); and,
- Explores elements of collaborative practice and identifies what aspects influence and enable cultural and system change.

Overall, although the Collaborative Pairs UK program is still in its infancy, early findings indicate potential individual benefits for clinician and consumer participation and the potential to influence organisational and culture change at the broader health system level. Furthermore, there are some similarities between the English and Australian health contexts, signifying that the Collaborative Pairs UK program may be successfully adapted and implemented in Australia to realise potential individual and broader health system benefits.

Findings from the literature indicate a number of elements that drive successful collaboration including: individual-level elements such as the ability to apply leadership skills, commit to a shared vision, and engage in a shared learning approach and growth mindset. At the broader system level, organisations need to adopt suitable methods to recruit and train a consumer workforce, and provide a positive organisational and broader health system environment that normalises collaborative practices and processes.

The literature emphasises that to have a meaningful impact on broad health system change, there is a need to move beyond consumer participation to consumer leadership. The Collaborative Pairs program harnesses the power of consumers in this space and provides leadership opportunities for consumers to work collaboratively with health professionals towards solving common local health system problems. However, significant challenges face individuals and the broader system in implementing and embedding such consumer leadership roles and opportunities.

In recent years a number of countries, including Australia, have aimed to reorientate their health systems from being provider-driven, to ones that place the consumer and community at the forefront of the health care system (Gardner et al., 2019). Evidence suggests that where patients are actively involved in their own care, we see improved health outcomes and overall efficiency gains (Coulter et al., 2013, Hibbard and Greene, 2013). Although in many developed health systems there is both a political will and demand from the public to put the patient at the centre of their care, actually making the shift to a patient-centred system has proved to be a challenge (Foot et al., 2014, Gold et al., 2015, Weissman et al., 2017). A King's Fund review of patient involvement in health care (Foot et al., 2014) suggests slow progress is largely due to the difficulty of the cultural and behavioural changes posed by a shift of this nature. This is not just about changing a few organisational practices, but instead breaking down vested interests and long established ways of thinking and doing. This requires more than policy change, but for patients and health professionals to think and act in different ways (Foot et al., 2014, Gold et al., 2015, Weissman et al., 2017).

If Australia is to move to a more consumer-focused system, it is imperative the capacity of both consumers and health professionals is improved and there is cultural change to deliver more effective collaboration between these groups. The Collaborative Pairs Program developed by the King's Fund aims to do precisely this through enabling and supporting '*cultural change and a new relational paradigm for consumers and health care professionals*' (Consumers Health Forum of Australia, 2017a). The Collaborative Pairs Australia National Demonstration Trial (CPADT) builds on the work of the King's Fund and focuses on the implementation of an Australian version of the UK Collaborative Pairs Program. The aim of the CPADT is to bring together consumers, patients and community leaders, alongside wider health service groups (including clinicians, managers and service providers), to build productive relationships and to appreciate and practice how different roles and perspectives can bring about constructive change within the Australian context (Consumers Health Forum of Australia, 2017a).

The Consumers Health Forum (CHF) have commissioned an independent evaluation of the Australian CPADT. The evaluation will examine the experience of the program to date and develop recommendation that will inform any future implementation of the program.

The key objectives of the evaluation include:

- Provide an assessment of the program's relevance, receptiveness and acceptability in the Australian context;
- Assess the program's effectiveness in building collaborative relationships that will impact on practice and lead to system changes in the way health services are designed, developed and implemented;
- Inform any further implementation of the program (i.e. a sustainable business and delivery model); and
- Build the evidence base on collaborative practice, leadership and transformational change.

The evaluation includes two complementary phases involving 1) a review of existing literature with a focus on the collaborative pairs project and 2) an implementation evaluation of the Collaborative Pairs Australia National Demonstration Trial.

This report provides details of the literature review setting out key themes for exploration in phase two - the implementation evaluation. The structure of the report includes a brief overview of the methods undertaken in the review, before going on to present the broader literature on consumer engagement. We consider what is meant by consumer engagement and what some of the challenges are to realising this in a health care context. We then move on to outline the elements of collaboration required to influence system change. These considerations are important in setting the conceptual context against which this program sits. Having established this, we consider the Collaborative Pairs program itself. We provide an insight into the English system and the drivers for this, before setting out the details of the program and the evidence to date surrounding this. As we outline, there is not significant empirical evidence to demonstrate the effectiveness of the program yet, but the key tenants of this align with the factors that are outlined as important in driving effective collaboration with consumers. We conclude by setting out what these findings means for the Australian context.

Review methods

Given the relatively recent nature of the Collaborative Pairs Program there is limited literature relating to this initiative. There are significant volumes of literature on related topics such as consumer engagement, collaboration and leadership. However, these are individually and collectively substantial literatures it would not be possible to systematically review within the confines of this project. As such, a scoping review approach was adopted. These approaches are often used when a body of literature has not yet been comprehensively reviewed, or exhibits a large, complex, or heterogeneous nature not amenable to a more precise review approach (Grant and Booth, 2009).

The scoping review followed the framework outlined in Arksey and O'Malley (2005). Given the breath of key terms a 'snowballing' approach was taken to the organization of search terms and key databases. Targeted searches produced over 5000 articles, but after screening for relevance only 31 were included in the final review.

Review aims include to:

1. Explore the elements of collaborative practice and identify what aspects influence and enable cultural and system change- with particular focus on consumer participation and consumer leadership.
2. Examine existing information and evidence of the English CP program exploring:
 - a. English health context and rationale for program developments in this area;
 - b. CP program content, methodology and implementation;
 - c. evidence around CP program effectiveness and learnings from England

The following sections begin by reporting on (1) collaborative practice and consumer participation at the individual and health system level and then moves on to present (2) evidence around the UK CP Program including some contextual information on the English health service setting.

Part 1. Consumer participation and consumer leadership: A review of the literature

Consumer participation at the individual and health system level

Authentic patient-centred care requires input and involvement from consumers, with a particular focus on empowering consumers to be informed and influential decision makers at the individual and system level (Rather et al., 2012). Contemporary international mental health policy has driven the importance of recognising and involving consumers across all levels of mental health services (Happell and Scholz, 2018) and more recently the Australian National Health Standards have broadened this focus across health (Australian Commission on Safety and Quality in Health Care, 2017a). Standard Two of the Australian National Health Standards highlights the requirement that consumers be partners in health service planning, design, delivery and evaluation. This standard outlines the need to involve consumers at the individual (micro) and system (macro) level to have meaningful individual and system improvement.

Distinguishing between micro and macro levels of consumer participation

There are two fundamental definitions of consumer participation. At the individual (micro) level, this refers to consumers being actively engaged in clinical service planning and treatment decisions, where consumers are partners in the clinical process rather than being merely compliant with clinical decisions made by experts (Lloyd and King, 2003). Providing consumers with opportunities to engage in shared-decision making related to disease treatment and self-management can increase emotional well-being, promote improved physical and emotional outcomes, and enable consumers to play an active and collaborative role in managing their own health (Consumer Focus Collaboration, 2001). Overall, consumer participation at the level of individual care can lead to improvements in the effectiveness and efficiency of health care and health.

At the system level (macro), consumer involvement means contributing to decisions made about the way services operate, including planning and reform processes, where the consumer is acting not just in relation to personal treatment but to broader processes that impact on larger groups of consumers and carers (Lloyd and King, 2003). However, there is a need to use the term 'consumer leadership' to describe consumer participation aimed at the broader system level (Happell and Roper, 2006). Use of the term 'consumer leadership' is a more accurate description of systemic participation and can contribute to the acknowledgement, respect and value for consumers being involved to contribute beyond a tokenistic attempt to 'represent' a broader group (Lloyd and King, 2003). Identifying the value of consumers as leaders contributes to a broader acknowledgement of a movement towards consumers commanding more status and demanding a significant role in agenda-setting in health system reform (Happell and Roper, 2006). Strong and effective partnerships across the health system requires consumer involvement to move beyond tokenistic 'participation', to active 'leadership' (Ocloo and Matthews, 2016).

Moving beyond consumer participation to consumer leadership

Consumer leadership is an emerging field, in Australia and internationally. New Zealand has shown a trend to move from consumer participation to consumer leadership, particularly in the mental health field. Gordon (2005) articulates that shifting from consumer participation at the individual level to broader consumer leadership at the system reform level is needed to promote more fruitful, genuine and effective engagement of consumers in mental health services. There is a particular need for consumers and health care professionals to work in partnership to share responsibilities and decision making to achieve a safe, high-quality, efficient, and patient-centred health care system (Ocloo and Matthews, 2016). This includes driving a culture shift from typically seeing consumers as 'users and choosers', to being valued as 'makers and shapers' of health services (Janamian et al., 2016). In Australia, this requires further investment in consumer leadership to build the capacity of consumers as co-creators to work in effective consumer-clinician partnerships.

Having set out some of the definitional issues in this space, we now move on to consider what some of the challenges are for achieving consumer participation.

Challenges for consumer participation at the individual and organisational level

Challenges for consumers

The willingness and ability for consumers to engage in various levels of involvement may be influenced by consumer beliefs about their role, health literacy, education, organisational policies and practices and culture, society and social norms, and regulation and policy (Ocloo and Matthews, 2016). The health system is complex and demands those working within it to have a diverse mix of skills, knowledge and competencies (Sharma et al., 2014). Challenges to consumer participation, let alone consumer leadership, in health services are largely due to the unequal distribution of power and resources. Often this is reflected in the lack of infrastructure to develop peer-run initiatives and the lack of tailored mentoring, training and development opportunities, career pathways, and standards of practice (O'Hagan, 2010). Consumers have varying levels of motivation, knowledge and acuity of illness, knowledge of health care system, and individual skills and capabilities (Sharma et al., 2014).

The majority of patient involvement in health care in the UK has taken place at the level of feedback and information-giving, providing little opportunity to meaningfully influence decision-making (Ocloo and Matthews, 2016, Gardner et al., 2019). Involved patients typically struggle to influence decisions and are largely expected to work within existing system. This approach represents a narrow 'managerialist or consumerist' model focused on 'improving the product', in contrast to a wider democratic and values-based model that emphasise the need for empowerment of service users in decision-making at the community level (Ocloo and Matthews, 2016). Democratic models recognise the need for change at the individual, service, and broader cultural system level.

Challenges for organisations

The aim of consumer participation in health care is to evolve from consumers being passive recipients to co-creators of system reform, but organisations can typically be slow to respond and resistant to these changes (Sharma et al., 2014). Consultative approaches are common, but these can give rise to a sense of public disillusionment, consultation fatigue or poor attitudes of health staff challenging the adoption and maintenance of partnerships with consumers (Renedo et al., 2015). As individuals in the health care system are incredibly varied and often are transient in the sense that their involvement is only periodic, it may be a challenge for organisations to identify and engage with relevant consumers beyond existing connections and networks (Sharma et al., 2014). Inconsistent terminology and different understandings of language can further impede ability to establish and maintain effective partnerships (World Health Organization, 2013). Moreover, health care organisations typically lack skills and capabilities to manage the requirement and desire for increased partnerships with consumers (Sharma et al., 2014).

Despite increased recognition and policy requirements for consumer inclusion in the design and delivery of health systems, the implementation of consumer participation initiatives has faced significant barriers, including poor resourcing and resistance from health professionals (Scholz et al., 2017a). Health professionals often perceive consumer knowledge to be too subjective, and view consumers as lay patients rather than knowledgeable partners that may be able to contribute practice knowledge, personal experiences, and scientific or experiential knowledge of illness and system processes (El Enany et al., 2013). Professional cultures and stereotypes can stifle opportunities for collaboration as these are commonly adopted by health professionals, where they see themselves as the leaders and decision-makers rather than team players (World Health Organization, 2013). These attitudes need to be addressed within organisations and early in health professional training to be more open and inclusive of consumer involvement at a higher shared decision-making level.

Despite the consumer leadership movement gaining some traction, power differences are still evidenced by the way service providers choose the means and degree that consumers can participate in its organisation or processes (Sharma et al., 2014). Barriers to increased opportunities for consumer leadership may include: that it requires a culture adjustment for some organisations and staff, that organisational priorities may conflict with consumer interests, and ill-defined roles and expectations present possible problems. Despite challenges, it is important the system does not become entrenched in negative attitudes regarding perceived additional effort and challenges in creating and nurturing consumer leadership roles, and emphasis should be on identifying opportunities at every turn for how consumer leaders may be able to be involved to co-create value to potentially enhance health services (Sharma et al., 2014).

Summary of findings and lesson for Australia:

The literature distinguishes between micro and macro level consumer participation:

- Micro involves consumers in clinical service planning and treatment decisions
- Macro involves consumers in the way services operate including planning and reform processes

Consumer collaborative programmes need to be clear on their focus and the vision for partnerships

Consumer leadership is an emerging field that focuses on advocating for and demonstrating ways that consumers may drive collaborations, rather than taking a more passive role.

Barriers to consumer leadership include the need to make cultural changes that may be in conflict with structural, organizational and staff interests.

Creating the environment for consumer leadership is a challenging but important element of effective health system performance

Elements of collaboration needed to influence system change

Despite an identified need to invest in consumer leadership, the implementation of such opportunities has proven to be challenging in Australia and internationally, with significant barriers at the individual and broader system levels. Due to these challenges, there is emerging but limited evidence on the enablers and change mechanisms associated with successful consumer leadership and consumer partnerships. There is a broader evidence base on the enablers and frameworks related to the development of collaborative relationships between health professionals and health service providers (e.g. Gardner et al., 2019). However, it is methodologically difficult to measure the success of such partnerships (Purcal et al., 2011). Evaluations on the efficacy of partnerships tend to focus on the processes through which they are created and operated rather than their outcomes (Dickinson and O'Flynn, 2016). However, these concepts can be applied to provide some insight into potential key enablers and change mechanisms related to successful collaborative relationships with consumers.

Across this evidence, there is widespread agreement on some of the common individual and organisational elements that help form successful collaborations (Roussos and Fawcett, 2000, Mattessich et al., 2001, Purcal et al., 2011, Luxford and Newell, 2015, Gillam et al., 2016, Gardner et al., 2019). These are also illustrated in Figure 1 and are elaborated on further below.

Individual-level elements relate to ability of individuals to:

- Develop leadership skills to form relationships
- Commit to a shared vision and demonstrate shared leadership
- Engage in a shared learning approach and growth mindset.

Organisational-level elements relate to broader organisational ability to:

- Recruit, train and support appropriate consumer workforce
- Provide a positive organisational environment
- Normalise organisational collaborative practices and processes.



Figure 1: Common individual and organizational elements associated with successful partnerships

Individual-level elements

Develop leadership skills to form relationships

Effective relationships have been identified as critical to the success of collaboration; relationships are the catalyst to successful partnerships (Dickinson, 2014, Crooks et al., 2018). Consumer leaders need the same skills as anyone else does in a leadership role, but may typically lack some of these generic skills due to lack of opportunities or experiences (O'Hagan, 2010). Many of these challenges may be overcome with training and development in generic competencies of leadership, including relationship development. Structured leadership training can be useful for both consumers and health professionals to develop skills to establish formal collaborative relationships (Pomey et al., 2015, Israilov and Cho, 2017). Leadership training for consumers and health professionals should be engrained with equality and empowerment values to help foster positive, trusting and lasting relationships (O'Hagan, 2010, Perrault et al., 2011). Leadership training can result in participants having a greater understanding of the health care system and its nuances, improved relationship and interpersonal skills, and an increased ability to initiate and maintain lasting partnerships (Pomey et al., 2015, Israilov and Cho, 2017).

The development of skills to forge informal relationships between collaborators is also important (Perrault et al., 2011, Gillam et al., 2016). Informal relationships can be demonstrated by establishing personal connections to create a cohesive, informed collaboration

with communication occurring at both a formal level (e.g. meetings) and informal level (e.g. conversations). Open communication that encourages positive informal relationships appears to help maintain goal focus, get work done, and maintain commitment between collaborators. When personal relationships are present and functional, there is greater mutual support to overcome challenges and conflict when issues arise (Perrault et al., 2011). Skills associated with the ability to form positive informal relationships include being able to demonstrate respect through everyday interactions, such as listening and paying attention, showing genuine interest in others' needs and wellbeing, and demonstrating organizational empathy to try to understand the pressures and constraints faced by others in the partnership. Strong formal and informal relationships enable participants to have difficult conversations and help weather the storm together in the face of uncertainty (Gillam et al., 2016).

Commit to a shared vision and demonstrate shared leadership

The process of developing a common vision can foster collaboration by building relationships and trust among partners (Gillam et al., 2016). The process of developing a shared vision, common goals, common language, and clarifying roles and expectations takes time and effort, but is essential for building and ensuring ongoing success of a collaboration (Perrault et al., 2011). Mutually agreeing on a collective purpose and a defined set of collaborative goals, with an open and flexible attitude, supports a commitment to learn together and solve problems together. Shared leadership then allows individuals with specialised skill sets to contribute differently, but equally, to that shared vision, and reinforces the value and influence of each member as both an individual and collective leader. Shared leadership should be based on the principles of mutual respect, understanding and trust, and can be facilitated through open and shared decision-making (Perrault et al., 2011). Shared leadership must operate in an atmosphere of agreed commitment to mutual growth and learning.

Engage in a shared learning approach and growth mindset

A shared learning approach is valuable to the process of collaboration, with mutual individual and organizational learning a valuable outcome of participating in a collaborative endeavour (Perrault et al., 2011). When individuals come together to collaborate, they must commit to tolerate uncertainty and wade through the tensions inherent in developing partnerships (Gillam et al., 2016). It is therefore important individuals approach partnerships with a growth mindset, meaning individuals maintain a belief that partners can learn to work together despite sources of uncertainty. Committing to a shared investment in a growth mindset has been identified as a key strategy in developing effective collaborative relationships (Gillam et al., 2016). A shared learning approach may be reflected by a pattern of dynamics that involve a supportive learning environment and commitment to creative problem solving to work towards the shared vision (Perrault et al., 2011).

Organizational-level elements

Recruit, train and support appropriate consumer workforce

In order to achieve effective consumer engagement, there needs to be a political shift from power and resources dominated by professionals and managers, to at least an equal power sharing with consumers (O'Hagan, 2010). For this to happen, consumers need to be in leadership roles within positions of power at all levels of the health system. Leadership opportunities assume people have the power to set the agenda, make major decisions and control resources. However, consumer leadership roles can typically lack a definition of the role and purpose, lack supportive infrastructure, lack understanding of the system and health literacy competencies, and experience burnout from expectations that outweigh capacities and resources (O'Hagan, 2010). It has been commonly reported that organizations need to provide adequate resources to facilitate opportunities for the development of skills and knowledge of consumers to participate meaningfully in the re-design of health services at the system level (Sharma et al., 2014). To support this shift in power, there needs to be more opportunities for consumers to collaborate in clinical, service and system decision-making, and provide more resources and infrastructure to support consumer training and development (O'Hagan, 2010).

As with any workplace health role, organizations need to identify and motivate a number of appropriate consumers and then provide them with the required skills, resources and ongoing support to contribute to system reform (Sharma et al., 2014). Organizations need to be clear in their intention to develop partnerships, but recognize the need to have organizational flexibility in processes for engagement and recruitment. Consumer agility refers to aligning, sensing and responding to opportunities to develop partnerships in a timely and appropriate manner. Organizations must have capabilities to identify and engage a diverse mix of consumers and be open the different ways in each may be able to contribute value, individually and also through their interactions and engagement with other consumers and providers. Organizations need to be more agile in their approach to identifying and seizing opportunities to respond quickly to develop partnerships and opportunities with consumers, particularly to embrace consumer leadership roles (Sharma et al., 2014).

Provide a positive organizational environment

Effective collaboration relies on positive environments where there are quality experiences for those involved (Perrault et al., 2011). Consumers need to be supported in the right environment to facilitate transformation of their 'consumer' identity to a leadership role to increase their influence and contribute to the creation of cultural workplace conditions conducive to partnerships (Renedo et al., 2015). Empowering consumers is not simply a matter of patients acquiring cognitive skills or technical knowledge, it involves a dynamic interplay between psychological, social-cultural and organizational processes. Organizations need to create change that is responsive and open to consumer participation and leadership (Sharma et al., 2014). Active, powerful and competent leadership is critical for enabling the development of partnerships for system innovation. Leadership needs to be modelled across all levels of an organization, with a collective approach and understanding of the value that engagement with consumers contributes to the success of the organization and its way of being.

The onus to form partnerships to influence system change needs to shift from individuals to organizations (Happell and Roper, 2006, El Enany et al., 2013). Organizations and employees have a responsibility to recognize opportunities for consumer collaboration (Gillam et al., 2016). Key elements in organizational culture that may contribute to encouraging successful consumer partnerships include (Renedo et al., 2015):

- Organizational staff ability to model desired improvement and behaviors of mutual recognition and respect towards consumers;
- Organizational focus on non-hierarchical, multidisciplinary collaboration between and among healthcare professionals and consumers;
- Organizational commitment to rapid improvement to translate lessons into implementation; and,
- Constant and iterative process of data collection and reflection facilitated by the use of quality improvement methods to improve consumer partnerships and opportunities for consumer leadership.

Normalise organizational collaborative practices and processes

To influence broader system change, employees need to be recruited, trained and supported within organizational contexts where the practice of partnerships with consumers is clear, embedded and normal (Ocloo and Matthews, 2016). Without adequate organizational training for both existing employees and consumers, inviting consumers to fit into and adapt to standard organizational cultures and processes runs the risk of disengaging both employees and consumers (Renedo et al., 2015). The way consumers are engaged and provided opportunities for leadership needs to be embedded in the way organizations do business and not as a tokenistic afterthought (Sharma et al., 2014). This can include organizations nurturing the development of collaborative relationships by hiring people with collaboration skills, providing training in collaboration, and providing staff the time to build genuine connections with consumers (Perrault et al., 2011).

Findings from service coordination programs examining the importance of partnerships in facilitating program effectiveness indicate a lack of formal processes at an organizational level can hinder these. Processes that rely on individual staff to establish and maintain effective partnerships without formal internal processes can risk sustainability if staff move on (Purcal et al., 2011). Building a strong positive work culture with normalised collaborative practices and aligned organizational principles may be key to developing successful collaborations (Gillam et al., 2016). Developing shared agreements and formalised processes around rules of engagement and guidelines for how health professionals and consumers work together in shared leadership roles can lead to more tolerance for ambiguity and more trust in the process of developing partnerships organization-wide. Organizations can redefine expectations of consumer involvement and adopt the principle of 'failing forward' to bolster a shared learning culture to encourage new organizational practices related to collaborative partnerships.

Summary of findings and lesson for Australia:

Individual and organizational elements associated with successful partnerships include:

INDIVIDUAL

The role of relationships is key to success with the consumer leaders needing to have leadership skills and/or training

A need to provide leadership development for consumers who have not had exposure to structured training

It is important to develop a shared vision, common goals that supports in setting boundaries and developing trust

A shared learning approach – "in this together" – it is important that both partners commit to tolerate uncertainty and work through tensions inherent in most partnerships

ORGANIZATIONAL

Need for a political shift from power dominated by professionals to an equal power sharing with consumers

Organizations need to provide adequate resources to facilitate opportunities for training and development for consumers

Organizations need to be clear in their intent and commitment to consumer collaboration, but flexible in their approach around engagement and recruitment

Positive environments are a crucial ingredient to success

Empowering consumers is not just a technical exercise of training and development whilst these aspects are important – the creation of cultural workplace conditions that are conducive to collaborative partnerships are also key

To make system changes organizations not just individuals need to create the right environments for this to happen

Employees need to be trained and supported

Beyond tokenism and engrained in the way organizations 'do business'

Part 2: Collaborative Pairs Review

Having set out a broad account of the literature relating to consumer engagement and collaboration including some of the challenges involved and the potential enablers of effective joint working, this section now moves on to specifically consider the literature related to the Collaborative Pairs program. Before considering this program in more detail, it is important to understand the English health context that the program sits in. The context of policy and reform in England has been a catalyst for the development and shaping of the CP program and in considering what lessons might be drawn from this it is important to understand this context.

The English health context

English health system reform

The sustainability of the English health system, the NHS, is dependent on its ability to adapt and evolve the traditional design and delivery of health services to include more engaged relationships with patients, carers and citizens (NHS England, 2014). A number of significant social and health reform movements have contributed to this need to shift from a traditional 'factory' model of health care approach that involved limited engagement with the wider community, to a more inclusive and consumer-focused approach to health care (Foot et al., 2014). These fundamental challenges are common to other industrialised countries' health care systems, including Australia.

Need for efficient, coordinated and sustainable health systems

With an ageing population and increased burden of chronic and complex long-term health conditions, there is increasing pressure on both England and Australian health care systems to meet health service demands (Foot et al., 2014). The traditional divide between primary, secondary and tertiary care has been largely unchanged since the birth of the NHS, yet services need to be more integrated and coordinated around the patient to meet growing multiple health needs (Glasby and Dickinson, 2014). If system efficiency is not improved, growing demand will produce a mismatch between resources and patient needs of nearly 30 billion pound a year by 2020/21 (NHS England, 2014). Actively supporting and empowering individuals to self-manage their health, including staying healthy, managing conditions, making informed treatment choices and avoiding complications, has the ability to minimise service use and manage resources more effectively (Foot et al., 2014).

Need to improve quality of care

The definition of quality in health care typically relates to the three key aspects of: patient safety, clinical effectiveness and patient experience (NHS England, 2014). The quality of care across these domains in both England and Australia have typically been reported as variable, with significant differences across and between these systems. The NHS has made commitments to improve monitoring and transparency in quality performance, incentivise quality improvements, invest in leadership, and embed mechanisms to enable affordable, sustainable and high quality care (Dickinson and Carey, 2016). However, high quality care also involves the application of evidence-based medicine alongside patient knowledge and experience. Health care quality experts agree that patients must be present, empowered and involved at all levels to achieve safe, effective and high quality care (Foot et al., 2014).

Need for local leaders working in collaboration

A whole-of-system shift is needed to harness the power of local leadership (Dickinson and Carey, 2016). The NHS acknowledges the need to engage with communities and citizens in new ways to directly involve them in decisions about the future of health care services (NHS England, 2014). Although there is a long history of attempts to work collaboratively across the health system and with other partners (e.g. social care), it is generally accepted that, in the main, these attempts have not been sufficiently effectively in driving sustained change and improvement. (Glasby and Dickinson, 2014). New partnership approaches are needed to empower local leaders to work together progressively to embed local solutions. This requires a new perspective where leaders are empowered and encouraged to look beyond the interests of individual organizations and towards the future development of whole health care economies (NHS England, 2014). Importantly, there is a critical role to engage local consumers in leadership tasks such as visioning, governance, strategic planning, decision making and health service re-design (Consumers Health Forum of Australia, 2017a). Consumers leadership requires a whole-of-system approach that goes beyond building the capacity of consumers to be leaders, to one that promotes and embeds broader culture change (Consumers Health Forum of Australia, 2017b).

Need to acknowledge patient preferences to be involved in shared decision-making

Involving patients in shared decision-making results in better decisions, improved health and health outcomes, and the more efficient allocation of resources. The majority of people wish to be more informed and involved with their own health care, yet it is common for patients to express disappointment about the lack of opportunities to participate in decisions about their care (Coulter and Collins, 2011). National patient surveys in the UK indicate at least half of patients who experienced a hospital episode would have liked more involvement in decisions about their health care and treatment, with no improvement in this trend over the last 10 years (Coulter and Collins, 2011). Common reasons for lack of shared-decision making include health care professionals typically overestimating the extent of patient involvement in shared decision-making and the time spent engaging in decision-making consultations, while underestimating the desire for patients to be involved in their own care and the effectiveness of shared decision-making. Despite widespread support for involving patients in decisions about their care, shared decision-making is not yet practiced universally in the UK.

Summary

There is a wide consensus across NHS leadership groups, patients, clinicians and local communities that consumers should have a stronger voice and be involved in shared-decision making at both the individual-level and wider system-level. However, despite this consensus, there has been a lack of systematic progress in involving patients in shared-decision making. This has been hypothesised to be due to a lack of clarity on what and how to involve people in their health, and the significant challenge in fostering a whole-of-health reform to do things differently. In 2013, The King's Fund began exploring the concept of consumer leadership to understand how to support its growth and development within the health system (Consumers Health Forum of Australia, 2017a). In September 2015, The King's Fund launched the Collaborative Pairs program, a national development program that aimed to explore how to develop collaborative relationships and lead health system change in England (Seale, 2016). We now move to consider the evidence relating to this program.

Program aim and objectives

The Collaborative Pairs (CP) program is a leadership training program that supports the development of practices that underpin the culture of shared leadership and collaboration (Consumers Health Forum of Australia, 2017a). Participants of the CP program are clinicians and consumers who are paired together to form a joint clinician-patient partnership to enhance health program and service development improvement in regional and service delivery settings. The aim of the program is to provide an opportunity for clinicians, managers, patients and consumers to learn together to build productive relationships and to appreciate and practice how different roles and perspectives can be a powerful catalyst to enable change. The objectives of the program are to build skills in developing partnerships, and to break down the cultural barriers that often exist between those providing the services and those receiving them. The underlying principle of the program is based on the assumption that consumers, managers and service providers are all equal in an effective health system.

Program content and methodology

The ability to form collaborative relationships, especially with patients, carers and communities, is often acknowledged as a set of 'softer skills' (Seale, 2016). Although termed 'softer' this does not necessarily mean these skills are easy to acquire or to operate in practice. In a traditional structure such as the NHS, there is the tendency to prioritise focus on structure, performance and tasks rather than the nature of how tasks are achieved and the effectiveness of relationships. The CP program focuses on creating nurturing relationships between pairs that focus on relational capabilities.

As outlined above, patients, service users, carers and community leaders often find they have little access to leadership development, unlike many health professionals (Seale, 2016). The CP program fills a gap by providing an opportunity for both consumers and health professionals to develop leadership capabilities, and to do together in a shared learning environment. Pairs are formed from the same organization or system with a shared task or project to work on. The pairs commence the program with a five-day development course focused on building collaborative capabilities, learning about what makes collaborative relationships work well, and creating a space to critically reflect.

The CP program provides participants with leadership training and a peer support network to:

- Develop knowledge and skills of dialogic communication and other models to support collaborative and partnership working;
- Develop skills associated with holding critical conversations;
- Develop influencing and negotiating skills
- Develop skills to manage difficult behaviour and conflict management
- Increase political intelligence and enhance skills to develop stakeholder relationships
- Improve understanding the health context.

Participants practice Action Learning and Peer Consulting as models for developing effective partnerships, and Appreciative Inquiry, Open Space and World Café methodologies are introduced and practiced, and their advantages and disadvantages explored.

Program implementation in England

COLLABORATIVE PAIRS PARTICIPANTS

The background of CP participants to date has been varied, including health care professionals from Clinical Commissioning Groups, clinical research networks, hospital and mental health Foundation Trusts, and community health. Consumer participants have included those who have experience in health care organizations, of working with a local Healthwatch (statutory bodies that speak on behalf of health care consumers), as lay members of executive groups, as members of working parties and patient participation groups, as well as a chief executive of local support services and patients who are active in third sector organizations. Excerpts from example projects are highlighted in Appendix One.

Program outcomes

ANTICIPATED BENEFITS FOR PARTICIPANTS

Anticipated benefits vary across user groups. Consumer leaders are thought to benefit from a practical development opportunity to build personal leadership and communication skills, learn how to influence and build constructive relationships with health care professionals, and gain access to a reflective peer community to work with other consumer leaders and health care professionals to explore the distinctive consumer leadership role (Consumers Health Forum of Australia, 2017a). Clinical leaders benefit from the opportunity to learn new ways of working with consumer leaders, expand communication practices and confidence to work collaboratively with consumer leaders and community stakeholders, and experience the challenge of shifting roles from manager/clinician to collaborative partner. Together, consumer leaders and clinical leaders are provided the opportunity to learn in a practical and supportive environment to make progress on a real-time challenge, build a productive, collaborative relationship within the health system, and join a network of collaborative pairs from across the country to contribute to national thinking about what a new relationship with patients and communities might look like.

Although the program is still in its infancy and benefits have not yet been empirically demonstrated, the program co-director states the CP program benefits participants as it helps them to overcome obstacles to building collaborative relationships:

“Participants have talked about the opportunity to work in a structured environment, in their pairs, on a specific project. They have found having time and space to reflect really valuable. They have strengthened their local relationship and developed their ability to work collaboratively. They have found that the tools and techniques used in the programme have supported them to make progress with their projects, as well as showing them how to work effectively together. They have learnt how to influence and collaborate with others across their organisations, particularly those who might initially have been sceptical. Also, participants have valued the opportunity to learn from the experiences of others and create a support network. All of this has increased their knowledge and experience and reinforced their confidence and resilience.” Mark Doughty, Leadership Associate, The King’s Fund (Doughty, 2016)

BROADER BENEFITS OF CONSUMER PARTICIPATION

In lieu of evidence around the quantifiable benefits and impact of the CP program, the broader literature provides some insight into the benefits of consumer participation that may support the development of an evaluation framework for this program. A growing body of evidence indicates involving patients across the spectrum of health care, from the individual level of self-care to the collective level of the broader health system, has a number of benefits (Ocloo and Matthews, 2016). Involving consumers in healthcare design, delivery and evaluation can improve service planning and development, communication, and the attitudes of healthcare providers (Australian Commission on Safety and Quality in Health Care, 2011).

Benefits of consumer participation in the health sector include increased efficiencies in health services, improved health outcomes, increased patient choice, improved patient experience, increased trust in the health care team, reduced health care costs to the patient and system, increased value and use of medical research, and increased patient satisfaction and compliance with treatment (Janamian et al., 2016, Ocloo and Matthews, 2016, Scholz et al., 2017b). Involving consumers in the delivery of clinical tertiary health care can reduce hospital costs, costs per patient, and length of hospital stay (Australian Commission on Safety and Quality in Health Care, 2017b). A literature review exploring the effect of community participation involving individuals and organizations working together to inform health service planning, decision-making, and program implementation reported improved health outcomes, service access, utilisation, quality and responsiveness, with recommendations that policy makers should strengthen policy and funding mechanisms to support consumer participation in primary health care (Bath and Wakeman, 2015). Overall, active consumer participation can lead to more accessible and effective health services (Consumer Focus Collaboration, 2001).

Program impact

ANTICIPATED PROGRAM IMPACT

Mark Doughty, program co-director, has provided feedback from participants regarding the impact of the CP program:

“Participants have said it has created a real change in their thinking and attitudes towards working with different groups. In the past it was often the case that when groups came together to talk about a project, problem or issue, it could quickly degenerate into people debating from fixed viewpoints reflecting their differing professional or functional backgrounds. Participants have talked about how the programme and its focus on how to build collaborative partnerships has helped them feel confident in: reducing conflict and disagreement in the workplace; supporting a different outlook and set of practices built on consensus, agreement and the willingness to look at things differently; and seeking to understand the viewpoints and experiences of different groups. This has led to powerful outcomes, such as agreements around how to move forward with what had previously been perceived as an intractable problem.” Mark Doughty, Leadership Associate, The King’s Fund (Doughty, 2016).

In relation to the ability of the CP program to result in positive collaborative relationships, Mark Doughty, program co-director, comments:

“We have generated lots of learning about what enables and what gets in the way of the new collaborative relationships. For instance, collaboration is supported when differences are acknowledged. In order for conversations to work fear, change, loss of power and the issue of identity need to be recognised and acknowledged. We will be reporting on the first programme when it finishes at the end of February, so watch this space!” Mark Doughty, Leadership Associate, The King’s Fund (Doughty, 2016).

QUANTIFYING OUTCOMES OF THE COLLABORATIVE PAIRS PROGRAM

Questions to help explore the key components that make a collaboration between health care professionals, patients and communities work well has been presented by The King’s Fund, including:

- Are collaborative relationships important?
- Are there roles for patients as leaders in your organization?
- What defines the relationship between patients and HCPs in your context?
- How does your organizational culture impact on collaborative work?
- How does power impact on collaborative relationships?
- What roles are possible for patients as leaders?
- What needs to change to allow more collaborative relationships?

Summary of findings and lesson for Australia:

There is limited information on the Collaborative Pairs project and evidence relating to implementation and impact.

Yet, the programme is built on existing evidence around the importance of involving consumers in all aspects of decision making – micro and macro

Participants involved in the English Collaborative Pairs program have varied including a variety of health care professionals and different levels of consumer experience of the health system

POTENTIAL BENEFITS:

Consumer and health professional leaders benefit from practical developmental opportunities and to grow their understanding of each other’s perspectives and lived experience

While no formal evaluation of the King’s Fund program has been undertaken, there are a number of positive participant testimonies.

Application of Collaborative Pairs program to the Australian context

It is important to examine a country's local context to determine its needs and capabilities in order to address barriers to share collaborative practices in new and existing programs (World Health Organization, 2013). It has been identified that further support, development and evaluation of collaborative partnership programs are needed to determine the key influencing variables, strategies and processes that influence the design and implementation of collaborative practices.

Australia has some consumer leadership programs (e.g. the Health Issues Centre's consumer leadership course), but these typically take the form of short courses that consumers attend and do not involve working on relationships with a clinician or provider. Collaborative Pairs Australia provides an opportunity for PHNs (Primary Health Networks) and LHDs (Local Health Districts) to grow and sustain consumers, service providers and managers as leaders work collaboratively in co-designing their local service system to have an impact on their local health economy. The program aims to enable communities and consumers to have greater ownership in the health system in their local area, promote a culture of continuous quality improvement and encourage innovation (Consumers Health Forum of Australia, 2017b).

Key outcomes for PHNs and LHDs of the CP program would be:

- The development of consumer leaders who are system-literate and confident in engaging in effective dialogue with clinical, managerial and other stakeholders about the healthcare they provide and to be able to engage in joint projects and co-design strategies and services;
- The development of clinical and managerial leaders who have respect for consumer and community leaders, view them as an asset and, importantly, have the knowledge and skills about how to engage them optimally in commissioning process and service development initiatives;
- Assistance with accountabilities around the extent to which PHNs are systemically involving consumers and communities in their governance and commissioning decisions, including steps taken to support such participation; and
- A contribution to PHN workforce development and retention efforts and a culture of improvement with PHNs.

It is anticipated leaders will benefit from participation in the program in the following ways:

- Increased capacity to build effective relationships based on trust, credibility and respect;
- Increased ability to see the big picture and act strategically and systemically;
- Develop skills to lead and manage their own health and wellbeing and build on this experience to lead and influence others; and
- Develop the ability to lead by example through demonstrating in their behaviour and language the changes they are trying to achieve.

Summary

Many countries have identified the need to engage consumers more effectively as a way of driving sustained improvement within their health systems. There is a significant literature dealing with both collaboration and consumer engagement and the drivers and enablers of these are, by now, well established. Yet, many systems find themselves struggling to embed these practices. In part, this is because this involves a significant culture change. Making a reality of consumer engagement and driving effective collaboration takes hard work and constant attention.

In England, the King's Fund has devised the CP program to support this process. This scheme pairs up consumers and clinicians to work together on a project that should deliver some improvement, but the crux of this program is about changing the culture of collaboration within these settings. This program is relatively young and as yet does not have significant empirical evidence to demonstrate that there have been significant changes to organizational outcomes or cultures as yet. However, the premise of the program and the activities and actions it aims to promote are in line with those enablers set out within the literature. Further, although some elements of the program are specific to the English context, there does not appear to be anything inherent within this that would prohibit its implementation in Australia – with appropriate alterations.

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Appendix One

A summary of example Collaborative Pairs UK projects.

“In our collaborative pairs project, we established a collaborative, quality improvement working group of patients, carers, community and trust staff to review our current processes around shared decision-making for medicines. The group is evaluating the current evidence base; developing tools to support the process; agreeing how the tools will be evaluated; and will review the evaluation. If successful, the tools will be implemented across the organisation. This project is not only about a collaborative approach to decision-making but highlights the importance of collaboration in developing clinical processes. We hope to use it to springboard further collaborative work across the organisation until this becomes normal practice rather than the exception.”

**Chief Executive, West London Collaborative, and Chief Pharmacist,
West London Mental Health Trust (Consumers Health Forum of Australia, 2017a).**

“We are embedding the collaborative pairs work within our patient experience and engagement strategy. Barts Health NHS Trust is large and spread across several sites and this approach ensures that the patients’ voice is embedded at the most fundamental level.”

**Patient Experience Lead, Barts Health NHS Trust, and, Chair,
Whipps Cross Patient Panel (Consumers Health Forum of Australia, 2017a).**

“North East Hampshire and Farnham Clinical Commissioning Group (CCG) has recently been awarded Vanguard status, one of 50 sites that will take a lead on the development of new models of care, acting as inspiration for the rest of the health and care system. In our area the focus will be on designing and implementing new models of care across the primary and acute care system. Co-production is crucial for the success of the project, the aim is to engage patients at every point in the design and implementation of the new look service—that is the part of the process where we will be focussing our attention. For Healthwatch Hampshire, the project is an opportunity to do what they do best – give citizens and communities a stronger voice, through creative consultation and community engagement, to influence and challenge how health and social care services are provided within their locality. We are well aware of the ambition of the project, it will require our organisations to evolve beyond one of commissioner and critical friend and move towards a more collaborative model. We will need to work together in the best interest of the communities we serve and develop our skills and abilities to ensure we avoid the easy trap of tokenistic or “tick box” engagement. Involving patients is one thing, we have both been to our fair share of meetings in which a patient has been plucked from somewhere at the last minute to represent the voice of the entire patient population. Our goal is to move to away from the more traditional methods of patient engagement and embrace the concept of citizens as partners and equals. The result of this work will be a CCG in which things look very different... perhaps we will start to see patient leaders on the Vanguard steering group, decisions at every level being supported and guided by patient feedback and experience and a future model of care developed with, rather than delivered to, patients. For us, this work begins immediately with an event for patients and patient representatives to come and learn more about the project and shape the key messages to be used in the wider community. This is the first step in what will be an interesting, eye-opening and challenging year ahead... this was demonstrated with our first activity at The King’s Fund”

**Collaborative pairs including Edward Wernick, GP and Clinical Director for Quality and Patient and Public Engagement,
North East Hampshire and Farnham Clinical Commissioning Group and Steve Manley, Community Outreach
and Engagement Officer, Healthwatch Hampshire (Wernick, 2018).**