COTA
For older Australians

Consumer Engagement in Aged Care Project

Phase One Report Attachment 1

Literature Review

No More Gravy!

Consumer and Carer Experiences

of the Aged Care System

2015 – 2016

COTA Australia, Consumer Engagement in Aged Care Project
Report written and compiled September 2016
David White, Project Manager and Karen Fraser, Project Consultant
Funded by the Department of Health under an ACSIHAG grant 2015 – 2017
Consumer engagement for healthy and active ageing – co-design, co-production and co-operation

Attachment 1 – Literature Review on Co-production with Older People.

Literature on co-production has increased over recent years. However, little evidence was available to determine how aged care services might implement programs based on this methodology and what support they may have needed when implementing such an approach.

To ensure that this project was underpinned by a strong evidence base, COTA Australia commissioned the following literature review to determine the extent to which co-production had been used within the aged care sector and with older people nationally and internationally, and to identify successful implementation projects where this had occurred.

Engagement of Older People in Experience-based, Co-design

A Summary Report of Existing Literature

Goetz Ottmann and Associates

Melbourne, 18 December 2015

Table of Contents:

Introduction

Co-production has become synonymous with innovative approaches to public service delivery in Australia and European Union countries (Hunter and Ritchie 2007; Loeffler, Parrado et al. 2008; Needham 2008; Alford 2009; Dunston, Lee et al. 2009). Indeed, recent trends show a shift away from the private sector-inspired managerial forms of policy development of the 1980s and 1990s (Alford 1998; Bovaird 2006), and the return to more participatory approaches to public policy making. However, whereas earlier forms of co-production have their origins in the United States of America (USA) during the 1970s - a time of growing budget deficits, fiscal austerity, and declining trust in governmental institutions (Sharp 1980; Whitaker 1980; Parks et al. 1981) - the current iteration is premised on Anthony Giddens' 'Third Way' (Giddens 1998) as well as the insight that the involvement of consumers in the design and implementation process of public services has the potential to (1) improve the quality and responsiveness of public services (Leadbeater 2007), (2) increase effectiveness of services and reduce public spending (Gershon 2004), and (3) strengthen and invigorate citizenship, social capital, and social democracy (Vamstad 2004). Thus, co-production addresses and fuses the three main problem areas faced by social democratic nation states in late modernity. It promises to improve service quality, reduce social spending, and generate a more engaged citizenship. While the promise of co-production has proved compelling for many governments, results have often not been able to match its potential. Hence, the question that looms large is:

- How can co-production be successfully implemented within a human services context?

This report homes in on this question. Synthesising the key findings of recent literature reviews focusing on co-production, co-creation, co-design, and patient/consumer engagement it foregrounds key factors that function as barriers and enablers of co-production approaches involving older people.

Background:

Historically, the ideal of 'citizen engagement' is rooted in a vast body of thought that aims to empower ordinary citizens by involving them in decisions that directly affect their lives (Ottmann 2009). In the delivery of health services, participatory ideals became enshrined in Sherry Arnstein's ladder of citizenship participation (in A Ladder of Citizen Participation, 1969) and the Alma Ata Declaration. However, whereas Arnstein envisaged a participatory culture in which health service users would play a key role in the decision-making process affecting their care, most subsequent attempts to institutionalise participatory ideals in health services in North America, Europe, and Australia defaulted to relatively low levels of citizen participation (Entwistle, Renfrew et al. 1998; Johnson and Silburn 2000; Abelson, Forest et al. 2002; Church, Saunders et al. 2002; Morone and Kilbreth 2003; Nathan 2004).

According to its proponents, 'co-production' has the capacity to reinvigorate Arnstein's vision of more inclusive and empowering health and social care (Dunston, Lee et al. 2009).

Definitions:

As emerges from this brief introduction, the term 'co-production' has a number of meanings that need to be differentiated. In the US, the concept of 'co-production' emerged during the 1970s (Ostrom 1973). At that time, the term largely referred to the ***joint provision*** of public services and the stimulation of social engagement (Whitaker 1980). During the 1990s, 'co-production' increasingly acquired a connotation of 'consumer empowerment' with ordinary citizens admitted into the decision-making sphere and being involved in the policy-making aspects of public service delivery (Alford 1998; Cooper and Kathi 2005; Dunston, Lee et al. 2009). In this transformative sense, 'co-production' is about more than generating social capital. It is about individuals, communities, and organisations developing the skills, knowledge, and ability to work together to develop new models and services drawing on their own experience and expertise with the aim to negotiate improvements in public services (Needham and Carr 2009; McIntyre-Mills 2010). Hence, at its core, co-production challenges and transforms existing practices and structures brining to bear the experience of consumers, patients, and participants on decisions that shape products or services. This conceptualisation of 'co-production' is at the core of this report.

Co-production is 'a way of working whereby citizens and decision makers, or people who use services, family carers and service providers work together to create a decision or service which works for them all. The approach is value driven and built on the principles that those who use a service are best placed to help design it' (National Occupational Standards,UK).

Co-production is also referred to as co-creation, co-design, or patient/consumer engagement. Indeed, there is a certain amount of conceptual confusion about how these concepts should be used. The Social Care Institute for Excellence proposes that co-production denotes a process that can be broken down into the following substrates:

- Co-design: planning of services.
- Co-decision making: allocation of resources.
- Co-delivery of services: including volunteers in the provision of services.
- Co-evaluation: involvement of volunteers in the evaluation and review of processes or services (SCIE 2015).

In the current literature, terms such as co-production, co-creation, co-design, and consumer engagement are often used interchangeably and insights from the literature associated with these terms are used to inform this report. It should be noted that this report does not deal with more basic, non-participatory forms of engagement (e.g. information dissemination, consultation).

A number of authors have attempted to distil a set of principles that underpin co-production. Some authors have opted for processes applicable to certain contexts, whereas others have drawn on philosophy to create overarching concepts. The following are broad principles crafted by the Social Care Institute for Excellence that can be applied in most settings:

- Equality: everyone has knowledge/assets to bring to the process
- Diversity: co-production should be inclusive
- Accessibility: ensuring that everyone has the same opportunity to take part in the process
- Reciprocity: ensuring that people receive something back for putting something in (SCIE 2015)

Methodology

While the evidence base within a social care context is still comparatively sparse, research focusing on patient/consumer engagement within a health setting provides a rich fabric of findings that has been the focus of a large number of systematic reviews. Given this state of the science, this report draws on reviews of co-production approaches in a number of human services settings (health, allied health, social care) to establish an evidence base that can be transferred to the Australian aged care context.

In order to identify relevant literature reviews, a number of databases (Cinahl Complete, Australian Public Affairs, Medline, Human & Social Science Collection, Health and Society, and Google Scholar) were searched. Search terms included 'co-production', 'co-creation', 'co-design', 'patient engagement', and 'consumer engagement'.

In order to be included, literature reviews had to focus on co-production within a human services setting. During the database search it became clear that literature reviews focusing on co-production specifically involving older people are scarce indeed and that only three reviews met these inclusion criteria (Lyttle and Ryan 2010). As a result, reviews of co-production approaches that involve people with complex support or care needs were included.

Findings

The research literature focusing on participant engagement focuses predominantly on ***health settings***. Research in this area has given rise to large body of literature summarised in a recent meta-analysis incorporating 117 literature reviews (Sarrami-Foroushani, Travaglia et al. 2012; Sarrami-Foroushani, Travaglia et al. 2014). In addition, two literature reviews focusing on health settings have been published over the last two years providing insights relevant to the Australian context (Kovacs Burns, Bellows et al. 2014; Johnson 2015). The focal points of this literature have considerable overlap with participant

engagement in social care setting and many of its findings can be translated into that context. It should be noted that only one of these 119 reviews focuses specifically on the engagement of older people. This review by Lyttle and Ryan focuses on 30 articles published between 2000 and 2007 (Lyttle and Ryan 2010). Hence, there is a considerable gap in the review literature and a literature review focusing on research articles published from 2007 onwards should be considered. An additional four literature reviews were located focusing on participant engagement in ***social care settings*** (Age UK ; Blair and Minkler 2009; Voorberg, Bekkers et al. 2014; SCIE 2015).Of these, two focused specifically on older people (Age UK ; Blair and Minkler 2009). One systematic literature review focused on co-production and co-creation drawing on 122 social care studies (Voorberg, Bekkers et al. 2014). The following section integrates the findings relevant to social care settings of this body of literature. Insights derived from additional literature focusing on the engagement of older people are added.

Level of evidence

It should be emphasised that this report is based on an enormous body of research. It draws on 121 literature reviews each containing dozens of research-based articles. In theory, this should make for a very solid evidence base. This, however, is not necessarily the case. The meta-analysis conducted by Sarrami-Foroushani, Travaglia et al. (Sarrami-Foroushani, Travaglia et al. 2012) contains a number of important weaknesses. For one, it is impossible to know exactly how many research articles the analysis is based on. This is largely because of the methodology employed allows for multiple inclusions (double counting) of studies. A brief check of the included reviews reveals that there is considerable overlap in the literature they include. As a result, it is possible that a core of research articles was included in several of the literature reviews, biasing the outcome of the meta-analysis towards these research reports. Another limitation is the fact that most authors did not appraise the quality of the included literature/literature reviews. In fact, only one of the additional literature reviews included in this report provides an indication of the quality of the reviewed research (Voorberg, Bekkers et al. 2014). These factors limit the strength of the evidence depicted in this report.

It should be also pointed out that reviews produced by UK foundations or centres included in this report (Age UK ; SCIE 2015) tend to be less focused on the published research literature and draw more either on their own work and/or on UK-focused case studies and practice examples. Nevertheless, there is much overlap between the research-focused literature reviews and these practice-focused reviews. Yet, the latter reviews produce recommendations that are more grounded in the UK policy context.

One size does not fit all

'Co-production' methods are not set in concrete and are seldom clearly articulated beyond a set of basic principles (see, for instance, NDTi 2010) that share common ground with action research approaches (Johnson and Silburn 2000; Considine and Lewis 2003; Nathan 2004). In the meta-analysis of 117 reviews, Sarrami-Foroushani Travaglia et al. (Sarrami-Foroushani, Travaglia et al. 2012; Sarrami-Foroushani, Travaglia et al. 2014) come to the conclusion that consumer engagement approaches are highly context dependent and that approaches proven to work in one setting may well not work in another. However, it is possible to identify commonly-mentioned enablers and barriers to successful co-production approaches. The following segment summarises the key themes present within the reviewed literature.

Co-production in practice

Organisations considering the use of a co-production approach should be aware that engaging older people in a co-design process takes more time than consulting experts (Kovacs Burns, Bellows et al. 2014). Also, co-production processes do require dedicated resources. Some researchers state that a co-production infrastructure has to be in place ***before*** the commencement of the actual process. What is more, co-production often requires considerable cultural change within organisations. In other words, co-production is an approach that requires considerable organisational effort and resources.

Co-production infrastructure:

A number of researchers have advanced the argument that co-production processes are necessarily based on resources (e.g. dedicated staff, time, resources, capacity, travel, transportation, room rental, catering) that are crucial for the successful outcome of co-production and that need to be in place ***before*** the commencement of co-production interventions (Age UK ; Sarrami-Foroushani, Travaglia et al. 2012; Kovacs Burns, Bellows et al. 2014; Johnson 2015; SCIE 2015). These resources constitute the ***co-production infrastructure*** (Kovacs Burns, Bellows et al. 2014). Some authors have pointed out that failure to adequately address these foundational issues can result in 'a series of ad hoc, unauthentic, and disconnected activities' ultimately resulting in the failure of co-production interventions (Johnson 2015).

While there is not a 'one size fits all' model and co-production approaches have to be purpose-designed, it is possible to delineate the *types* of components that constitute the co-production infrastructure enabling co-production processes across different settings. Indeed, a number of literature reviews have attempted to corroborate what the key components of this enabling co-production infrastructure might consist of (Age UK ; Sarrami-Foroushani, Travaglia et al. 2012; Kovacs Burns, Bellows et al. 2014; Johnson 2015; SCIE 2015). Authors largely agree that co-production must be embedded deeply in an organisational structure and professional practices. Co-production should be embraced by

the organisation's leadership and form part of its governance framework and strategic vision. The following items circumscribe the co-production infrastructure components highlighted in the literature:

- Co-production runs through the culture of the organisation
- Culture is built on a shared understanding of what co-production is, a set of principles for putting the approach into action, and the benefits and outcomes that will be achieved with the approach.
- Participants' knowledge and experience is valued throughout the organisation
- Organisation is ready to admit participant to the decision making process
- Staff is up-skilled to work within a co-production framework
- Co-production principles are embedded in performance and accountability indicators
- Dedicated resources are available for co-production processes
- Organisations develop a culture of being risk aware rather than risk averse.
- Co-production processes are evaluated and monitored

Preliminary decisions:

Because co-production does require resource intensive preparatory work, many authors (see, for example, Age UK ; Sarrami-Foroushani, Travaglia et al. 2012; Kovacs Burns, Bellows et al. 2014; Johnson 2015; SCIE 2015) recommend for a co-production intervention to be carefully planned utilising a set of steps commencing with a systematic cost/benefit analysis. Most authors highlight the need to carefully:

- Specify the aim of the co-production approach,
- Determine the appropriate type and scope of co-production activity,
- Identify appropriate participants,
- Identify staff members/management who need to participate,
- Consider how the co-production is best facilitated,
- Ensure that key stakeholders are prepared for the co-production process,
- Determine the best method for the issue at hand,
- Consider how the process is best evaluated and identify/develop appropriate evaluation tools,
- Consider potential barriers and identify ways to remove them, and
- Identify potential enablers and how to harness them.

These steps are explored in more detail in the following sections.

1) Aim, Method, and Scope:

Researchers highlight the importance of clearly stating the aim, purpose, and target of a co-production intervention before implementation. Clearly defining the aim of the intervention will not only allow for an evaluation of the outcomes of the process, it will also assist the facilitation of the co-production process.

Subsequently, the authors emphasise the need to carefully choose the intervention type (e.g. partnering with consumers, supporting clients to monitor the quality of services) and method (e.g. focus groups, online questionnaire, Delphi survey). In particular, the authors state that it is useful to estimate and evaluate the costs (including hidden costs), benefits, barriers and facilitators of each intervention type and method. The authors argue that approaching and appraising consumer engagement consistently will enable organisations to identify the most effective type and method of engagement (Sarrami-Foroushani, Travaglia et al. 2012).

Next, the authors argue that it is important to clearly outline the scope of the co-production process (e.g. the degree to which participant decisions will shape the final decision) in order to set clear boundaries and expectations for the project.

2) Selecting participants:

Selecting appropriate participants to include in a co-production intervention is crucial for its successful outcome. The key question is whether participants adequately represent the target population. For example, participants may represent themselves, specific communities or minority groups, consumers with specific support needs, or consumers more generally. In 2006, the NHRMC published a report emphasising that the perspectives of consumers is diverse and that multiple engagement approaches are needed to capture these perspectives adequately (cited in Johnson 2015). Hence, if participants represent larger groups the co-production facilitator should plan to involve a range of consumer groups and check whether data saturation (a condition where no new information is being conveyed by in meetings) has occurred during the consumer involvement process. Co-production coordinators also need to be aware that some participants become permanent members of co-production forums and may become 'professionalised', as a result. That is, their perspectives on a given topic may no longer represent those of the larger target group. Selecting participants may also introduce biases as organisations tend to prefer to involve acquiescent consumers rather than those with an 'axe to grind' (Kaminski 2009; Kovacs Burns, Bellows et al. 2014). The outcome of this strategy may be that the co-production process excludes more critical voices, which may empty the co-production process of its transformative potential (Johnson 2015).

Co-production coordinators may find themselves in a position where they cannot choose participants and where participants self-select into a working group. Self-selection gives rise to a group composed of individuals who want to be involved but not necessarily who should be involved as individuals who want to participate may be more motivated to participate (e.g. extremely satisfied/dissatisfied with services), more able to participate (e.g. enjoying better physical or psychological health), or better resourced to participate (e.g. have access to transport, can afford to attend regular meetings), or have the time to participate. Hence, Kovacs Burns, Bellows et al. argue that it is absolutely crucial to ask the following two basic questions when recruiting participants:

- Who wants to be involved and
- Who should be involved (Kovacs Burns, Bellows et al. 2014).

The responses to these questions should assist the facilitator to take the necessary action to reduce recruitment bias. The authors argue that these questions help organisations to ensure representativeness of the process which in turn assists with accountability. In addition, co-production coordinators should consider whether participants should be paid/reimbursed for their involvement in order to ensure that individuals with less disposable income are included in the process, thus averting a potential sample bias towards more affluent participants.

In any case, if a self-selected sample is to represent a larger group, the question of data saturation becomes crucial and multiple engagement strategies should be considered. Alternatively, if this is too time consuming or costly, it might be more useful to seek 'consumer perspectives' rather than 'representativeness' (Johnson 2015). However, this shift in epistemological premise would mean that the co-production process is no longer endowed with larger explanatory power and results should be seen as themes that may or may not represent the views of the larger group.

Also, selecting staff member or management to participate in a co-production intervention can be crucial for the successful outcome of the process. Co-production interventions must have the support of key decision makers within an organisation. It is often necessary to directly involve these decision makers at key junctures of the co-production process to deliberate on and endorse decisions so that they are binding for the organisation.

3) Facilitating co-production

The facilitation of co-production draws heavily on group facilitation and group management. A key consideration that should be given to the facilitation process is whether an external facilitator is required. Some co-production interventions (e.g. evaluation of service quality, decisions in a highly charged organisational context) benefit greatly from involving external facilitators (Age UK ; Sarrami-Foroushani, Travaglia et al. 2012; Johnson 2015; SCIE 2015). The following are enablers are frequently mentioned in the literature:

- Value and reward people who take part in the co-production process
- Foster trust and understanding among group members
- Using plain language
- Using essential information first and by itself
- Ability to simplify potentially complex issues
- Ability to use communication strategies to engage people with dementia
- Use of augmented forms of communication (e.g. Photovoice) where appropriate
- Establish ground rules ensuring respectful group interactions
- Following an established plan to mediate conflicting points of view

- Keeping a balance between discussions focused on the issues at hand and social interaction
- Ensure that there are resources to cover the cost of co-production activities
- Ensure that co-production is supported by a strategy that describes how things are going to be communicated
- Build on existing structures and resources
- Ensure that everything in the co-production process is accessible to everyone taking part and nobody is excluded.
- Ensure that participants involved have enough information to take part in co-production and decision making.
- Ensure that all participants have an opportunity to contribute (group management)
- Ensure that participants have access to formal/informal support networks
- Ensure that everyone involved is trained in the principles and philosophy of co-production and any skills they need for the work they do.
- Think about whether an independent facilitator would be useful to support the process of co-production.
- Ensure that frontline staff are given the opportunity, time, resources, and flexibility to use co-production approaches.
- Provide any support that is necessary to make sure that the participants involved have the capacity to be part of the co-production process.
- Ensure that policies and procedures promote the commissioning of services that use co-production approaches.
- Ensure that there are policies for co-production in the actual process of commissioning.
- Carry out regular reviews
- Demonstrate to participants how their input has led to change

4) Fostering decisional readiness:

Numerous researchers highlight the need to ensure that participants have the required skill and knowledge levels enabling them to make informed decisions. This means that co-production interventions may contain targeted training and capacity building sessions to foster participants' ***decisional readiness***. Decisional readiness circumscribes a condition where participants are ready to make informed decisions. There are numerous components contributing to decisional readiness. Participants need to have an understanding of what the co-production process seeks to achieve and what the different phases of the process look like. What is more, a common working vocabulary needs to be established to facilitate communication. Participants need to absorb project-specific knowledge and may require support during the deliberation and decision making process.

Explaining co-production and its aims:

Several publications argue that conceptual clarity is crucial if co-production meetings are to be successful (Age UK ; Johnson 2015; SCIE 2015). The authors of these publications state that facilitators should be clear about the principles of engagement, the scope of the decision making, the way the organisation is involved, and foster clarity around the terminology employed. Explaining timelines and how their participation will generate change may help to overcome involvement fatigue.

- Principles of engagement
- Levels of engagement (informative, consultative, participatory, empowering)
- Organisational domain of engagement (micro, meso, macro) (identification of needs and preferences, service planning, design of care, procurement of services, measurement of outcomes)
- Outlining timelines
- Clarity about terminology

Informing and educating participants:

In order to be able to have an informed opinion about an issue at the core of a co-production process, participants often need to acquire new, potentially complex information and possibly new skills. Coordinators have the task to convey this information in a manner that is accessible to participants. A meta-analysis of the literature focusing on the provision of information on the topic of advance care planning (Tamayo-Velazquez, Simon-Lorda et al. 2010) highlights that a passive information provision strategy (i.e. through pamphlets, booklets, etc.) tends to be ineffective. The authors conclude that the best educational method is to combine information with frequent personal conversation (Tamayo-Velazquez, Simon-Lorda et al. 2010). In addition, authors have outlined that the provision of information must be relevant to older people if they are to absorb it. Indeed, a growing body of research suggests that engaging directly with older people's expertise, their personal and social experiences of their care, and understanding their goals within an everyday life context is crucial (Johnson 2015). Thus, discovery learning or related approaches where the person draws on their own experience and prior knowledge when exploring or interacting with an environment may be more successful than other approaches. For example, exploration of older people's understanding and preferences regarding their care could begin with an exploration of their physical sensations and day–to-day experiences of their care. Also, facilitators should be aware that older people's brains tend to perform better on demanding tasks in the morning and that it may be advantageous to schedule co-production meetings in the *am* (Anderson, Campbell et al. 2014). It might be also worth bearing in mind that there is some evidence that older people's (those aged 66 and older) preferred learning styles tend to focus more on 'feeling and watching' or 'thinking and watching' than younger adults (Truluck and Courtenay 1999). That is, learning activities that are supported by concrete visual demonstrations may be more accessible to older adults than if they are only based on orally transmitted information. It should be

noted that role play may not have the desired outcomes and may lead to confusion as many older people are unfamiliar with the method and its premise.

Peer-support or peer-education can be also considered when up-skilling older people to participate in co-production, as such interventions have proven successful in some settings (e.g. HIV education, mental health interventions, maternal health, foster care) (Sarrami-Foroushani, Travaglia et al. 2012). However, researchers emphasise that peer-support/education hinges on the training and support made available to potential volunteers and the management of the wider process (Wright-Berryman, McGuire et al. 2011).

Decision aids can enhance participants' capacity to make informed decisions. However, the development of decision aids is a complex process and should involve the input of participants (Sarrami-Foroushani, Travaglia et al. 2012; Johnson 2015). Tools can also facilitate the deliberation phase and assist participants to acquire the required knowledge (Sarrami-Foroushani, Travaglia et al. 2012). Research has shown that people with cognitive impairments may find it harder to weigh up information in order to make decisions (Bailey, Willner et al. 2011; Fisher, Bailey et al. 2012). Again decision aids in the form of physical scales or bar charts where arguments for and against a decision are added to two bar charts (or opposing sides of a scale) tend to increase participants' ability to make decisions (Bailey, Willner et al. 2011; Fisher, Bailey et al. 2012).

It should be noted that fostering service literacy (the ability to read, understand, evaluate and use service information to make appropriate decisions about one' aged care) is quintessential if participants are to make informed decisions about their care. When providing information about service literacy it is important to bear in mind that service literacy is based on two conceptual components (a) literacy regarding the services a participant is entitled to receive (skills, knowledge, preferences, motivation etc.) and (b) literacy regarding the service context (infrastructure, policies, materials, people and relationships). Service literacy needs to be embedded in high level organisational policies and practices; should be clear, focused, usable, and effective; integrated into education of consumers and professionals (Johnson 2015).

5) Barriers:

Most literature reviews highlight a range of factors that might constitute important barriers to participant engagement (Age UK ; Blair and Minkler 2009; Sarrami-Foroushani, Travaglia et al. 2012; Kovacs Burns, Bellows et al. 2014; Voorberg, Bekkers et al. 2014; Johnson 2015; SCIE 2015). There are a number of common themes that surface in this literature and it is possible to identify an emergent consensus. Authors largely categorise barriers in terms of (a) participant barriers, (b) staff barriers, (c) organisational barriers, and (d) contextual barriers:

Barriers at the level of the participant:

- Preference for participation (shaped by age, education levels, disability, ethnicity, cultural factors)
- Adequacy of representation (participants not representative of target population)
- Not having the time to participate
- Geographical distance
- Lack of trust (in organisation, process, facilitation, group)
- Lack of clarity around roles and function
- Stigma (e.g. mental health issues, dementia)
- Health status (condition-specific limitations, physical or psychological exhaustion)
- Lack of self confidence
- Lack of knowledge political or operational context
- Lack of skills to deliberate on technically complex decisions
- Lack of skills to participate effectively (e.g. computing)
- Lack of financial or other resources (e.g. transport, carer support, access to internet)
- Difficulty to communicate needs and preferences
- Inability to identify the benefit of co-production
- Lack of ownership of co-production process
- Involvement fatigue

Barriers associated with facilitation of co-production:

- Failure to value the life experience of participants
- Lack of common understanding regarding community engagement
- Lack of clarity around how to engage with consumers and who are the 'right' consumers to engage.
- Inability to inspire trust and understanding
- Absence of clear aims and objectives
- Non-collegial approach, unequal power relationships
- Lack of education/training of co-production facilitators/coordinators
- Lack of educational materials aimed at facilitators
- Lack of support (training, mentoring, decisional, resources)
- Lack of understanding of support needs
- Lack of resources to educate participants in relevant issues
- Lack of communication skills (e.g. listening, disseminating information without participant input)
- Lack of knowledge of preferred learning styles
- Lack of group management skills
- Lack of conflict resolution skills
- Lack of teaching/mentoring skills
- Lack of ability to deal with language and cultural differences

Staff Barriers:

- Negative attitudes toward participant involvement (e.g. dismissive of patient expertise)
- Non-collegial approach, unequal power relationships
- Reluctance by professionals to relinquish power and treat participants as equals
- Professional practice is guided by systemic imperatives rather than participants' needs and preferences
- Listening to participants/families is not embedded in organisational culture and professional practice
- Lack of decision making capacity. Key staff members/management are not engaged and do not participate in the process
- Lack of knowledge of participant involvement
- Refusal to contribute information
- Difficulty/unwillingness to explain difficult complex terminology
- Feeling threatened by possible reduction in influence; difficulty in relinquishing power
- Emotional or physical disengagement from project
- Lack of resources

Organisational Barriers:

- Lack of support at senior executive and/or board level
- Tendency to engage participants in a tokenistic way
- Organisational culture (values do not support shared decision making)
- Negative attitudes towards participant involvement (e.g. co-production seen as an inconvenience, time consuming, disruptive, or a waste of resources)
- Lack of knowledge of how patients may be involved (e.g. lack of training and guidance)
- Tokenism
- Refusal to contribute resources or information to the process
- Budget limitations (lack of resources to fund consumer engagement)
- Lack of integration of consumer participation with formal service planning, delivery and evaluation

Contextual Barriers:

- Gap between recognition of patient/consumer rights and the adherence of these rights in practice through engagement in decision making.
- Poor political commitment to participant involvement (lack of policies, regulatory frameworks, standards, and legislation)

- In appropriate funding instruments to pay for services (e.g. fee for service mechanisms may discourage or limit participant involvement)

6) Evaluation:

Most of the included reviews recommend some form of evaluation or review of co-production processes. The format of evaluations and reviews differs across contexts. Authors focusing on a social care context recommend regular, co-production-based reviews of processes and outcomes in order to appraise whether processes followed agreed upon protocols and in order to produce data that can be used for improving and fine-tuning co-production processes (Age UK ; Voorberg, Bekkers et al. 2014; SCIE 2015).

Authors focusing on health contexts tend to recommend outcome-focused evaluations to measure impact and efficacy (Sarrami-Foroushani, Travaglia et al. 2012; Kovacs Burns, Bellows et al. 2014; Sarrami-Foroushani, Travaglia et al. 2014; Johnson 2015). The health-focused literature tends to highlight an absence of tools that could be used to evaluate co-production interventions. This literature also emphasises that evaluations should be based on a set of outcome measures such as:

- Participation or response rate of consumers
- Consumer influence on decisions
- Outcomes in terms of service/program design or resource utilisation
- Consumer satisfaction with the engagement process
- Consumer satisfaction with care outcomes/resulting products
- Cost
- Critical factors for success
- Limitations of methods or processes

Conclusion

This report summarised and integrated the findings relevant to the provision of social care services for older people of recent literature reviews focusing on participant engagement, co-production, co-creation, and co-design. It outlines highlights that co-production interventions are highly context dependent and that a 'one-size-fits-all' model does not exist. Yet, the report features a number of central themes that appear to constitute an emerging consensus in terms of enablers and barriers to co-production processes. It should also be born in mind that despite the large number of research reports informing this field, the strength of the evidence continues to be unclear and more research is required to harden the evidence base depicted in this report.

Co-production, if implemented in a transformative manner, has the potential to make human services more responsive to the needs and preferences of clients, reduce resource wastage, and foster a more engaged citizenry. However, this report makes it clear that co-production has to be central to an organisation's *modus operandi* for such expectations to

become a reality. Co-production has to underpin the vision, mission, management approach, and the professional practice of frontline staff. It requires dedicated resources and necessitates the up-skilling of participants and staff. In addition, co-production particularly when involving older people takes time and patience. Inasmuch, co-production is not a quick fix for poorly targeted services or a task that can be dropped on a single staff member. For the considerable potential of co-production to be unleashed, a genuine participatory style of decision making has to be adopted – particularly on occasions when the opinions and preferences of participants contravene the organisational status quo. This takes unflinching commitment as well as the backing of co-production principles by senior executives and board members. If such support is not forthcoming, the transformative potential of co-production is likely to be eroded giving rise to yet another tokenistic client reference group.

References:

Abelson, J., P.-G. Forest, et al. (2002). "Obtaining public input for health-systems decision-making: Past experiences and future prospects." Canadian Public Administration 45(1).

Age UK Engaging with older people: Evidence review. London UK, Age UK.

Alford, J. (1998). "A public management road less travelled: clients as co-producers of public services." Australian Journal of Public Administration 57(4): 128-137.

Alford, J. (2009). Public Value from co-production by clients. Working Paper. Melbourne, Australia and New Zealand School of Government.

Anderson, J., K. L. Campbell, et al. (2014). "Timing is everything: age differences in the cognitive control network are modulated by time of day." Psychology and Aging online: DOI: 10.1037/a0037243.

Bailey, R., P. Willner, et al. (2011). "A visual aid to decision-making for people with intellectual disabilities." Research in Developmental Disabilities: A Multidisciplinary Journal 32(1): 37-46.

Blair, T. and M. Minkler (2009). "Participatory Action Research with Older Adults: Key Principles in Practice." The Gerontologist 49(5): 651-662.

Bovaird, T. (2006). "Developing new forms of partnership with the 'market' in the procurement of public services." Public Administration 84(1): 81-102.

Church, J., D. Saunders, et al. (2002). "Citizen participation in health decision-making: Past experience and future prospects." Journal of Public Health Policy 23(1): 12-32.

Considine, M. and J. M. Lewis (2003). Bureaucracy, Network, or Enterprise? Comparing Models of Governance in Australia, Britain, the Netherlands, and New Zealand. 63: 131-140.

Cooper, T. L. and P. C. Kathi (2005). "Neighbourhood Councils and City Agnecies: A Model of Collaborative Co-production." National Civic Review Spring: 43-53.

Dunston, R., A. Lee, et al. (2009). "Co-production and health system reform - from re-imagining to re-making." The Australian Journal of Public Administration 68(1): 39-52.

Entwistle, V. A., M. J. Renfrew, et al. (1998). "Lay Perspectives: Advantages for Health Research." BMJ 316(7129): 463-466.

Fisher, Z., R. Bailey, et al. (2012). "Practical Aspects of a Visual Aid to Decision Making." Journal of Intellectual Disability Research 56(6): 588-599.

Gershon, P. (2004). Releasing resources to the front line: independent review of public sector efficiency. London, HMSO.

Giddens, A. (1998). The third way. The renewal of social democracy. Cambridge, Polity Press.

Hunter, S. and P. Ritchie (2007). Co-production and personalisation in social care: changing relationships in the provision of social care, Jessica Kingsley.

Johnson, A. (2015). Consumer and Community Engagement in Health Services: A Literature Review to Support the Development of an Evidence Based Consumer and Community Engagement Strategy for the Women's and Children's Health Network, South Australia. Adelaide SA, SA Health, Women's and Children's Hospital, HCSA

Johnson, A. and K. Silburn (2000). "Community and consumer participation in Australian health services - an overview of organisational commitment and participation processes." Australian Health Review 23(3): 113-121.

Kaminski, J. (2009). "Harnessing the wave of co-creation." Online Journal of Nursing Informatics 13(3): 1-7 7p.

Kovacs Burns, K., M. Bellows, et al. (2014). "'Practical' resources to support patient and family engagement in healthcare decisions: a scoping review." BMC Health Services Research 14(1): 175-175 171p.

Leadbeater, C. (2007). Personalisation through participation: a new script for public services. London, Demos.

Loeffler, E., S. Parrado, et al. (2008). 'If you want to go fast, walk along. If you want to go far, walk together': citizens and the co-production of pbulic services. Ministry of Budget, Public Finance and Public Services. Paris, European Presidency

Lyttle, D. J. and A. Ryan (2010). "Factors influencing older patients' participation in care: a review of the literature." Int J Older People Nurs 5(4): 274-282.

McIntyre-Mills, J. (2010). "Participatory Design for Democracy and Wellbeing: Narrowing the Gap Between Services Outcomes and Perceived Needs." Syst Pract Action Res DOI 10.1007/s1213-009-9145-9.

Morone, J. A. and E. H. Kilbreth (2003). "Power to the People? Restoring Citizen Participation " Journal of Health Politics, Policy and Law 28(2-3): 271-288.

Nathan, S. (2004). "Consumer participation: The challenge to achieving influence and equity." Australian Journal of Primary Health 10(3).

National Occupational Standards SFHMH63: Work with peopel and significant others to develop services to improve their mental health. London UK.

Needham, C. (2008). Realising the Potential of Co-production: Negotiating Improvements in Public Services, Cambridge Journals Online. 7: 221-231.

Needham, C. and S. Carr (2009). Co-production: an emerging evidence base for adult social care transformation. SCIE Research briefing 31. London, Queen Mary University, Social Care Institute for Excellence.

Ostrom, V. (1973). The Intellectual Crisis in American Public Administration. Tuscaloosa, Ala., University of Alabama Press.

Ottmann, G. (2009). Democracy in the Making? Municipal Reforms, Civil Society, and the Brazilian Workers' Party. Hauppauge NY, Nova Science Publishers.

Sarrami-Foroushani, P., J. Travaglia, et al. (2014). "Implementing strategies in consumer and community engagement in health care: results of a large-scale, scoping meta-review." BMC Health Services Research 14: 402-418.

Sarrami-Foroushani, P., J. Travaglia, et al. (2012). Consumer and Community Engagement: A review of the literature. Sydndey NSW, University of New South Wales, NSW Agency for Clinical Innovation, Australian Institute of Health Innovation.

SCIE (2015). Co-production in social care: What it is and how to do it. London UK, Social Care Institute for Excellence.

Tamayo-Velazquez, M. I., P. Simon-Lorda, et al. (2010). "Interventions to promote the use of advance directives: an overview of systmatic reviews." Patient Education & Counseling 80: 10-20.

Truluck, J. E. and B. C. Courtenay (1999). "Learning style preferences among older adults." Educational Gerontology 25(3): 221-236.

Vamstad, J. (2004). Co-production as a defining principle - a new typology for provision of welfare services in Sweden. EGPA Conference. Ljubljana, Slovenia.

Voorberg, W. H., V. J. J. M. Bekkers, et al. (2014). "A systematic review of co-creation and co-production: Embarking on the social innovation journey." Public Management Review online: DOI: 10.1080/14719037.14712014.14930505.

Whitaker, G. (1980). "Co-production: Citizen participation in service delivery." Public Administration Review May/June(40): 240-146.

Wright-Berryman, J. L., A. G. McGuire, et al. (2011). "A review of consumer-provided services on assertive community treatment and intensive case management teams: implications for future research and practice." Journal of the American Psychiatric Nurses Association 17: 34-44.