

## **Consumer Participation in Drug Treatment: A Systematic Review**

## Keywords

Consumer participation, drug treatment service delivery, professional attitudes

## Abstract

### *Purpose*

It is unclear how consumer participation (CP) can be optimised to transform drug and alcohol treatment services and improve health outcomes. This paper presents the findings of a systematic review examining the types and benefits of activities, and the factors that facilitate CP in drug treatment services.

### *Design*

A structured search of four databases was undertaken to identify peer reviewed primary research literature in English. Screened articles were appraised. A content analysis was applied to examine the types and outcomes of CP and the associated factors affecting the process. Sixteen articles were included for review.

### *Findings*

A range of CP activities were identified, and benefits included increased consumer satisfaction, and improved health service delivery. Factors that facilitated the process of CP included positive attitudes of both consumers and providers and employment of people with a lived experience of drug use. However, the lack of consumer and organisational capacity, negative attitudes of providers and power imbalances between consumers and providers constrained CP efforts.

*Practical implications*

To maximise the benefits of CP in drug and alcohol treatment services, negative attitudes about CP and power dynamics between consumers and health providers need to be addressed. This can be achieved ~~by~~ through the strategic use of strengths-based interventions and consumer led education to enhance social capital.

*Originality/value*

This is the first known review to examine the benefits and facilitators of consumer participation in drug treatment services.

## Background

Consumer participation (CP) in health care transpires when consumers are 'meaningfully involved in decision-making about health policy and planning, care and treatment, and the wellbeing of themselves and their community' (ACT Government Health, 2011: p. 7). CP arose from social change movements in the 1960's and 1970's that included Black Power in the United States and women's and gay liberation (Tomes, 2006). In 1978 the World Health Organisation initiated CP in health care (Shea et al., 2005). This action is supported by the Declaration of Alma Ata that promotes equity and social justice in health care by ensuring people have 'the right and duty to participate individually and collectively in the planning and implementation of their health care' (WHO, 1978: p.1). There is reliable evidence that involving consumers in the delivery of health care leads to more satisfactory, safer, higher quality care and improved health outcomes (Institute of Medicine, 2001). As a result, CP has become a high priority for many governments and policy makers (Tambuyzer et al., 2014) and is necessary to achieve the co-production of health care services (Batalden et al., 2016).

Several governments around the world have introduced policies and guidelines to guide consumer involvement in drug treatment services. The government of the United Kingdom was the first to legislate CP in drug treatment services and as a result is considered a world leader (Hinton, 2010). The UK collects data about CP in mutual aid engagement activities, such as peer run groups and smart recovery, which is based on the principles of cognitive behavioural therapy. (NDTMS, 2016). Examples of successful drug treatment involving CP are provided in the national guidelines (Public Health England, 2015). Despite these efforts, CP in drug treatment

services in the UK are 'patchy and sometimes tokenistic' (Hinton, 2010 p. 25). This is because CP is often poorly resourced and not embedded into strategic objectives of the service (Hinton, 2010). As a result, services are streamlined and cannot be tailored to meet individual's needs.

Furthermore, some consumers are excluded from contributing to service delivery because they are incarcerated or live in rural areas with poor transport and services that are geographically dispersed (Hinton, 2010).

CP has been implemented for several decades in mental health services. One review in this care context showed that employing consumers within these services leads to greater consumer satisfaction and reduced hospital admissions (Simpson and House, 2002). Consumer-led services have also resulted in positive employment and accommodation outcomes for mental health consumers (Doughty and Tse, 2011).

Four reviews have explored CP in drug treatment services. The first focused on consumers' perspectives regarding provider training to ensure they are responsive to consumers' needs (Wylie, 2010). The second reviewed studies that focused on the involvement of people who use drugs in policy and program development noting the lack of evidence regarding their participation on policy committees (Ti et al., 2012). The third critically reviewed studies that reported results of consumer satisfaction surveys in drug treatment services (Trujols et al., 2014). The fourth investigated how consumers' perspectives are incorporated into surveys designed to inform service development (Hyshka et al., 2017).

While these reviews are informative, gaps remain in fully understanding the factors that enable or inhibit consumers' involvement in drug treatment services. An awareness of these factors is critical to realising the benefits of consumer involvement in these services.

### *Levels of CP*

Bryant et al. (Bryant et al., 2008a, Bryant et al., 2008b) have conceptualised the participation of consumers in drug treatment services in a hierarchical manner, illustrated as a ladder that depicts various levels of involvement (Table 1). At the lower rungs of the ladder consumer participation is classified as activities such as the use of surveys to gain insight into consumer satisfaction with services (Bryant et al., 2008a, King, 2011, Patterson et al., 2009a, Patterson et al., 2009b, Schulte et al., 2007). At the upper end of the ladder are more complex activities, such as the involvement of consumers in decisions about service planning and delivery and the selection of new employees.

### **Table 1. here**

There is a need to understand the factors that impact upon CP policy, the ability of organizations and individuals to successfully engage consumers in all aspects of service delivery and the socio-economic outcomes that arise from positive CP. The aim of this systematic review therefore is to identify the types of activities that are associated with CP, their associated outcomes and the factors that facilitate or constrain consumer participation in drug and alcohol treatment services.

## Methods

### *Search strategy*

A search of the electronic databases Medline Ovid, Embase Ovid, and Scopus and Drug Database was performed in January 2018 to retrieve peer reviewed research publications in English. One additional article was sourced from a reference list. While no date limit was applied, no literature regarding CP and drug treatment was retrieved prior to 2007. The search was conducted using the following key terms: 'consumer participation', or 'patient participation' or 'client participation' or 'user involvement' or 'peer' or 'empowerment' and 'drug treatment' or 'drug treatment services' or 'harm reduction services' or 'drug and alcohol services' or 'substance abuse treatment centers/centres'. Table 2 outlines the inclusion and exclusion criteria that were applied.

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The initial search located 1004 items that was reduced to ~~45~~16 after removing duplicates and those that did not meet the inclusion criteria (see Figure 1)

### *Appraisal of Studies*

The criteria Critical Appraisal Skills Programme (CASP, 2014) were used to appraise the quality of the nine qualitative studies; two were excluded as they did not fully outline the methodology. The CASP Case Control Study Checklist, CASP Cohort Study Checklist and the Joanna Briggs Checklist for Analytical Cross-Sectional Studies (Joanna Briggs Institute, 2017) were applied to the seven quantitative studies; none were excluded.

#### **Figure 1 here**

*Data extraction and synthesis*

Full text data were extracted from the 16 papers and first described according to general study characteristics. A directed content analysis was then employed, as outlined by Dawson et al.(2015), to organise the data on a table based on the CP ladder, thus enabling comparison of the findings across key areas. Activities were identified as lower, mid and higher on the ladder alongside the reported associated benefits and the factors that facilitated or constrained them. [Table 3 outlines the characteristics and findings of the 16 studies.](#)

[Table 3 here](#)

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**Results**

Of the sixteen studies were included in the review ~~four~~five employed quantitative research methodologies, ~~ten~~nine used qualitative approaches and two applied mix methods methodologies. Seven of the studies originated in Australia, seven in the United Kingdom, one in Finland and one in Canada. The study sites included government and non-government detoxification services, residential rehabilitation units, opioid substitution clinics, drug and alcohol policy committees, harm reduction service and drug and alcohol counselling services.

Consumers were involved in a variety of lower to mid activities that included completing satisfaction surveys, facilitating groups, operating a café and a drop-in centre and educating providers. A range of higher level activities were described, such as: involvement in the development of a consumer charter of rights, consumers serving as members of committees, attending staff meetings, and participating in



staff recruitment, quality assurance activities, research commissioning and coproducing services.

*Benefits of CP:*

**Improved service delivery**

In five studies (Bryant et al., 2008b, Greer et al., 2016, Patterson et al., 2009b, Tober et al., 2013) service quality was enhanced when the views of service users were incorporated through consumer representation on decision making committees, open councils or forums and service expansion projects. These improvements included: enhanced consumer-centred care (King, 2011), decreased waiting times and revised operating hours (Bryant et al., 2008b, Patterson et al., 2009b), increased consumer survey response rate about service reconfiguration (Patterson et al., 2009b) and better opportunities for social support, self-help, and networking (Patterson et al., 2010). Consumer groups were found to support consumers through the stages of addiction and recovery by assisting them to better access treatment services, providing additional information about services, offering advocacy in the case of problems with a provider, and providing alternative forms of support for consumers who did not wish to engage in prescriptive programmes such as Narcotics/ Alcoholics Anonymous (Van Hout and McElrath, 2012).

Consumer input was found to expand the current range of available services such as the development of an aftercare service (Tober et al., 2013), an inpatient unit, a day program, and mobile treatment service and the introduction of buprenorphine to increase treatment options (Patterson et al., 2009b). Consumer input also led to the development of improved harm reduction interventions, such as a take home

naloxone program and the provision of a wider range of safer inhalation supplies (Greer et al., 2016) and injecting equipment (Patterson et al., 2009b).

### ***Increased satisfaction and goal achievement***

Studies revealed that consumers who participated in planning and delivering services including the type of drug treatment they wished to undertake, enjoyed high levels of satisfaction (Brener et al., 2009, Patterson et al., 2009b) and goal achievement (Brener et al., 2009). A survey of 492 consumers found that consumer satisfaction increased when consumers participated in planning their treatment and that this participation increased awareness of their rights (Brener et al., 2009). Brener et al. (2009) also reported that the achievement of treatment goals was associated with being involved in a review of the service and having knowledge of grievance procedures.

### ***Empowerment***

Involving consumers in CP activities was found to foster consumer empowerment as their participation altered the power dynamics of the consumer-provider relationship (King, 2011, Patterson et al., 2009a, Rance and Treloar, 2015) and reduced the stigmatisation of service users (Patterson et al., 2009a). CP decreased the interpersonal distance between consumers and providers (Patterson et al., 2009a), allowing them to see each other's human qualities (Rance and Treloar, 2015) and finding common ground (Tober et al., 2013). As a result, consumers were able to gain confidence and a sense of ownership over aspects of the service (Patterson et al., 2010, Tober et al., 2013).

Consumer empowerment was affected by the ethos underpinning the health service itself. Providers who worked in harm reduction services were found to be less paternalistic than those who worked in more traditional setting such as a drug treatment service for pregnant woman (Leppo and Perala, 2009).

Health care organizations that facilitated consumer led training were found to have empowered consumers, improved relations between consumers and providers and decreased stigma and staff discrimination towards consumers (Roussy et al., 2015). As a result, providers stated that they gained a greater understanding of needs of people with both substance use and mental health disorders and felt more competent in their caring role. Consumers also became empowered as members of harm reduction committees, as their membership helped them to become involved in their community, develop confidence and skills, and become inspired by peer leaders (Greer et al., 2016).

Consumers reported that they became more confident to express their needs through their involvement in participatory activities. One consumer expressed this by stating that, 'I think it is important that users have a voice 'cause we are people too' (Rance and Treloar, 2015 p. 33). Consumers also reported this 'voice' could be political in nature (Rance and Treloar, 2015), thus invigorating their desire for social justice (Patterson et al., 2009a). Therefore, a voice helped consumers educate the public and raise awareness about issues that impact them (Rance and Treloar, 2015, Patterson et al., 2010), such as the need for the decriminalisation of drug use, reforms in prescribing policies, and making drug treatment more accessible and respectful (Patterson et al., 2009a). The consumers' voice also informed the

development of participatory activities that helped to create solidarity among consumers and enabled collective feedback to be presented to service providers (Patterson et al., 2010).

#### *Facilitators of CP:*

##### ***Supportive attitudes of consumers and providers***

Eight studies revealed that the supportive attitudes of consumers and professionals encouraged consumers to be more involved in drug treatment service delivery and planning (Greer et al., 2016, King, 2011, Patterson et al., 2009a, Patterson et al., 2009b, Patterson et al., 2010, Rance and Treloar, 2015, Tober et al., 2013, Van Hout and McElrath, 2012). Attitudes reflecting values that CP was fundamental to effective service delivery facilitated consumer-centred care through developing an understanding of service users' individual and collective needs (King, 2011, Patterson et al., 2009a). Therefore, CP was facilitated by an organisational culture that embodied optimistic views and an appreciation of consumer contributions (Van Hout and McElrath, 2012), and mutual respect (Patterson et al., 2009b) that allowed consumers and staff to work towards a collaborative ethos (Rance and Treloar, 2015).

Such organisations demonstrated these values through adequate funding and dedicated time to participatory initiatives (Greer et al. 2016, Patterson et al., 2009b). Other aspects of these organisations included well-defined internal and external communication pathways (Patterson et al., 2010), clearly articulated expectations (Greer et al., 2016), and the provision of feedback on the progress and outcome of consumer requests and suggestions (Patterson et al., 2009b).

### ***Employment of consumers with lived experience***

Three quarters of consumers in the Schulte et al. (2007) study were supportive of people with a lived experience of drug use being employed on a voluntary or paid basis. Consumer employment was underpinned by the understanding that they are well-informed, have the knowledge, understanding and credibility to be effective (Treloar et al., 2011) and are more empathic, as they have similar life experiences as consumers (King, 2011). The mentors who helped produce an aftercare service reported that their lived experience of recovery helped other consumers to see that it is 'possible to move on [and] to learn to live again' (Tober et al., 2013 p. 231).

Patterson et al. (2009b) reported that people with a lived experience working in drug treatment facilities required specific training that included information about the service structure and processes and formal meeting procedures such as agendas, chairing meetings and minute taking. It was also suggested that this training should be self-reflective, so consumers can review their learning and performance. Training ultimately helped consumer representatives progress to paid positions within drug services. (Patterson et al., 2009b).

### ***Constraints of CP***

#### ***Perceptions of consumers' capacity***

Service providers were reluctant to involve consumers, especially in higher level activities such as staff training, recruitment and performance appraisal, because they thought that consumers did not possess the skills or interest to successfully undertake such activities (Bryant et al., 2008b, Patterson et al., 2009b, Schulte et al.,

2007, Van Hout and McElrath, 2012). Providers in Patterson et al. (2009a) study 'questioned the legitimacy of involving people who 'choose' to use illicit substances and therefore have 'self-inflicted problems' '[p.57]. Even when active CP was embedded into services, providers expressed doubt about the sustainability of these activities as consumers were viewed as unstable, manipulative, untrustworthy, powerless, vulnerable and lacking in capacity to participate because of their chaotic lifestyles and social problems (Patterson et al., 2009a, Patterson et al., 2010, Treloar et al., 2011, Van Hout and McElrath, 2012). Fears that consumers may relapse or would endanger the recovery of those who were abstinent were also expressed (Van Hout and McElrath, 2012, Tober et al., 2013). Providers were also reluctant to involve consumers in service delivery because they lacked trust in them and were concerned about their strong opinions (Patterson et al., 2009b) and disparate (Patterson et al., 2010) and unrealistic (King, 2011) expectations about service delivery.

Consumers also expressed the view that it was not their place to be involved in staff matters because they perceived that they did not have: the necessary skills (Bryant et al., 2008b, Patterson et al., 2009a), stability (King, 2011, Treloar et al., 2011), interest, confidence or entitlement to participate (King, 2011). Mentors who co-produced an aftercare service reported they felt uncomfortable and confused about their boundaries when consumers disclosed information that they usually relayed to a therapist because they lacked counselling skills (Tober et al., 2013). In another study providers were worried that peer workers would disregard guidelines, interpersonal boundaries and confidentiality issues, because they lacked formal training (King, 2011).

It was also revealed consumers were unaware of opportunities to participate due to a lack of knowledge about CP in principle or in practice (Patterson et al., 2009a).

Several studies reported that consumers did not know how to make a service complaint (Bryant et al., 2008a, Brener et al., 2009), nor did they know the location of the suggestion box (Bryant et al., 2008a). In another study consumers and providers were unaware of the service user support team whose role was to advocate on behalf of consumers (Van Hout and McElrath, 2012).

Studies have also questioned consumer groups' capacity to represent the diverse range of people that engage with drug treatment services (Patterson et al., 2009b, Patterson et al., 2010, Van Hout and McElrath, 2012). It was reported that cliques often occur in drug user groups (Patterson et al., 2009a), and they are perceived as 'exclusive' (Patterson et al., 2010). Consequently, this limits group membership, as selection of members is frequently based on therapeutic orientation, drug user status or relationship with the group convenor (Patterson et al., 2010). It was suggested that service user forums need to increase their visibility to broaden their membership and include prisoners, gay, lesbian and transgender people, and migrants to ensure a more accurate representation of drug treatment consumers (Van Hout and McElrath, 2012).

#### ***Power imbalances between consumers and providers***

Providers reported that they were reluctant to involve consumers in service planning and delivery because of the hierarchical professional-client relationship, described as the 'them and us' divide that emphasized beliefs that healthcare providers know best

(Leppo and Perala, 2009, Patterson et al., 2009b, Rance and Treloar, 2015).

Providers were found to be resistant and concerned about moves towards establishing more equal power relationships (Rance and Treloar, 2015, Treloar et al., 2011), as they feared that professional authority might be undermined. Such views were said to perpetuate negative and judgemental views towards consumers (King, 2011, Patterson et al., 2010, Patterson et al., 2009a, Patterson et al., 2009b, Van Hout and McElrath, 2012).

Consumer representation on committees (Greer et al., 2016, Lancaster et al., 2017) was found to be 'weighted towards scientific voices' (Lancaster et al., 2017: p. 64) that maintained professional dominance in decision making. In addition, consumer knowledge was often seen as illegitimate, as it represented 'the antithesis of clear and systematic reasoning' (Lancaster et al., 2017: p. 65).

Power divides and conflicts between consumers and staff were reported to be intensified by abstinence-related punitive rules set by residential treatment services (King, 2011). Consumers were reluctant to make complaints against staff because they worried that staff would assert their power by restricting medication or excluding them from services (Patterson et al., 2009a).

### ***Low organisational capacity***

A lack of organisational direction from government and support for consumer positions that enable consumer advocacy was found to negatively affect the ability of managers to bring about change (Van Hout and McElrath, 2012). The low value of consumer support positions was also explained by inadequate terms of reference



(Van Hout and McElrath, 2012), poor organisational drive and obstruction to programs (King, 2011), and insufficient commitment from government (King, 2011, Patterson et al., 2009a). Other studies reported that poor allocation of financial and human resources constrained CP projects (King, 2011, Patterson et al., 2009a, Patterson et al., 2009b, Patterson et al., 2010, Schulte et al., 2007, Treloar et al., 2011, Van Hout and McElrath, 2012). These studies found that CP was not considered 'core business' and that projects were often disrupted because of staff resignations, poor staff hand over (Greer et al., 2016, Treloar et al., 2011) and organisational time constraints (Patterson et al., 2009b).

Patterson et al. (2009a) reported that the focus on attaining performance targets, undermined the resources, energy, and commitment required for CP. Staff also often underestimated the amount of work required to undertake a CP project and did not value training in this area (Treloar et al., 2011).

## Discussion

This review has revealed that CP has the potential to enhance drug treatment services and health outcomes. CP can increase consumer access to improved and expanded services, improve consumer satisfaction, relationships between staff, and consumers, reduce individual providers' negative attitudes and help consumers achieve their treatment goals. CP activities ultimately empower consumers by giving them a voice and the skills knowledge and confidence they require to actively and meaningfully contribute. However, CP is predicated upon a service delivery context that values consumer contributions through clear commitment that is articulated in policy and resourcing.

Even though CP policy has been enshrined into policy, attitudinal change at an organisational level which facilitates the translation of policy into practice at service level remains a challenge. Despite the existence of CP policies at the macro level, consumer involvement in drug treatment services is constrained by organisational cultures at the micro level. Consequently, CP initiatives are often poorly conceived and inadequately resourced, especially higher-level activities. Attempts to incorporate higher levels activities into drug treatment service delivery are often not sustained due to organisational instability, including frequent staff changes, insufficient handover of CP projects and the low value of CP as core business (Treloar et al., 2011).

If CP is to succeed in drug treatment services, the notion that consumers are incapable of contributing also needs to be challenged. Some providers will be reluctant to meet these challenges, as drug and alcohol services 'are framed by an environment that is strongly risk averse' (The Royal Australian and New Zealand College of Psychiatrists, 2012: p. 18). This is reflected in the physical environment of treatment services that are often fitted out with bullet-proof glass and buzzing doors, which reinforces the notion that consumers are associated with danger and crime (Crawford, 2013). As a result, providers are often reluctant to involve consumers in service delivery because they are perceived as 'criminals', 'addicts' and 'junkies' (Radcliffe and Stevens, 2008, Crawford, 2013, Harris and McElrath, 2012). Such conceptions of substance dependence necessitate change in order to improve attitudes concerning consumer involvement in service delivery.

Since the 1970's substance dependence has been viewed through a pathological lens (Siegal et al., 1995) and over the past twenty years in the American Diagnostic and Statistical Manual of Mental Disorders substance dependence has been increasingly conceptualised biological in nature (Nathan et al., 2016). Furthermore, drug rehabilitation treatment is dominated by programs that claim that individuals with substance dependence are 'diseased' and 'powerless' (Anonymous, 2014). Describing individuals with substance dependence in this manner reinforces criminal stereotypes such as the 'junkie' (Crawford, 2013). In addition, stigma and discrimination restrict involvement of consumers in policy and program development (Ti et al., 2012). Overall, a purely biological/diseased and stigmatised view of substance dependence reinforces the belief that drug treatment consumers lack capacity not only to contribute to their own care but also service delivery and planning.

To overcome the notion that drug treatment consumers lack capacity, a strength-based model is required to move beyond a focus on an individual's pathology or deficits (Rapp and Goscha, 2011) to a systematic assessment of a consumers' skills, attributes and assets (National Registry of Evidence-Based Programs and Practices, 2009). This model is based on the creation of egalitarian consumer-professional relationships with consumers' directing the helping process (Rapp and Goscha, 2011). These strategies flatten the hierarchical expert-patient relationship that dominates drug treatment services and constrains consumer participation (Putman, 1993). More harmonious and equal relationships help to foster an environment where the consumers' voice is more likely to be considered. A way to promote such relationships is for services to invest in social capital.

Social capital as conceptualised by Putnam are the 'features of social organizations, such as networks, norms, and trust that facilitate action and co-operation for mutual benefit' (Putman, 1993: p. 35). Shared connections between consumers can be developed through activities such as the service user support teams, as described by Van Hout and McElrath (2012). Here social capital can be built through the bonding of consumers. Bridging social capital or enhancing the connections between different consumers and staff in treatment services can be achieved by consumer training of staff that promotes an understanding of consumer needs and awareness of the importance of mutual respect (Roussy et al., 2015), and well-defined communication channels (Patterson et al., 2010). Engaging diverse groups of consumers in decision making committees within treatment services is key to linking social capital by increasing the degree to which people create relationships with institutions and individuals who have considerable amount of power over them (Woolcock, 2001). Building social capital will therefore help to reduce the power differentials that constrain CP.

Harnessing the opportunities for social capital can help drug treatment organisations improve performance as teamwork is an essential element of quality healthcare (Norrish et al., 2013). High levels of social capital are associated with improved drug treatment and harm reduction outcomes such as reduced risk of relapse (Panebianco et al., 2016) and overdose (Zoorob and Salemi, 2017), recovery from substance and alcohol dependence (Granfield and Cloud, 2001, Weston et al., 2018), and a decreased risk of sharing syringes (Kumar et al., 2016).

In mental health care the recovery movement has been particularly successful supporting people who experience mental illness to gain increased levels of social capital. This has been achieved as a result of the consumer driven nature of the recovery movement that focuses on self-determination through the provision of opportunities for people with mental illness to contribute to mainstream society through work and education (Davidson, 2016). This has enabled mental health consumers to gain a voice and a renewed sense of hope (Meehan et al., 2008). In the UK, drug treatment services are starting to follow by providing opportunities such as sustained employment as part of treatment (Black, 2016).

While activities to build social capital to address the treatment needs of consumers and better engage consumers in their own care are required, these will need to be tailored to fit individual contexts. The ladder of consumer participation depicts a range of activities that can be implemented to change power dynamics and empower consumers. However, it must be noted that different types of knowledge and expertise are central to the process of citizen participation require a comprehensive approach to capacity building. In addition, not all people will desire power or want to be involved in decision-making activities (Tritter and McCallum, 2006).

Even though it is useful to depict the power dynamics at the various levels of the ladder the activities and processes in drug treatment service delivery are not straightforward or linear. This is because the different levels of activity take place simultaneously and there is a variation in the degree to which consumers are willing to participate and the activities in which they are willing to engage. For example, some consumers will not want to participate, as they may wish to concentrate on

their treatment, some will be pleased to contribute by completing a satisfaction survey, while others will be highly motivated to volunteer their time, for example, by being a consumer representative on a committee that informs policy.

A framework for consumer participation would be improved by visualising participatory activities in a more dynamic fashion, with participatory activities displayed in an integrated manner rather than ranked within a hierarchy. This will allow for reference to “bundles” of activities from all levels of the ladder to better illustrate the complexity and need for tailoring according to the context. The ladder also does not consider the full spectrum of consumer participation. For example, the ladder does not describe consumers who choose not to participate, and consumers who are employed in drug treatment services because of their lived experience of drug use and recovery.

### *Limitations*

A limitation of this review is that only literature published in the English language has been included. In addition, there was no literature related to closed settings such as prisons and involuntary treatment, where unequal power dynamics are exacerbated. Therefore, the synthesis may have led to a loss of detail, particularly of contextual factors that are important to the outcomes of the various CP interventions.

### *Implication for research*

Future research needs to focus on how current policy decisions impact upon providers attitudes towards CP and on the commissioning and monitoring of services. Therefore, it would be useful to investigate staff experience, professional

development and communication skills and how these factors impact on their attitudes and the implementation of CP projects. In addition, the barriers to CP for prisoners, migrants, gay, lesbian and transgender people needs to be investigated as well as for those consumers who are not candidates for 12-step philosophy of treatment.

## **Conclusion**

If drug treatment services do not invest in social capital positive attitudes towards CP drug treatment services may not evolve to successfully address consumer needs. Consumers' capacity to contribute requires a supportive organizational environment to challenge notions of 'staff know best' so that quality care and services can be optimised. In addition, the current ladder of CP in drug treatment needs to be transformed so all forms of participation are equally valued and increased 'buy in' from strategic bodies and commissioning teams is required.

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## **Conflict of Interest**

No conflicts of interest declared.

## References

- Act Government Health. 2011. *Consumer & Carer Participation Framework* [Online]. Available: [health.act.gov.au/c/health?a=dlpubpoldoc&document=2771](http://health.act.gov.au/c/health?a=dlpubpoldoc&document=2771) [Accessed 8th November 2011].
- Anonymous, N. 2014. *History of N.A.* [Online]. [http://www.vvana.info/History\\_of\\_N.php](http://www.vvana.info/History_of_N.php). [Accessed 2nd August 2014].
- Batalden, M., Batalden, P., Margolis, P., Seid, M., Armstrong, G., Opipari-Arrigan, L. & Hartung, H. 2016. Coproduction of healthcare service. *BMJ Quality & Safety*, 25, 509-17.
- Black, C. 2016. *An Independent Review into the impact on employment outcomes of drug or alcohol addiction, and obesity* [Online]. Available: <https://www.gov.uk/government/publications/drug-and-alcohol-addiction-and-obesity-effects-on-employment-outcomes> [Accessed 5th July, 2018].
- Brener, L., Resnick, I., Ellard, J., Treloar, C. & Bryant, J. 2009. Exploring the role of consumer participation in drug treatment. *Drug and Alcohol Dependence*, 105, 172-175.
- Bryant, J., Saxton, M., Madden, A., Bath, N. & Robinson, S. 2008a. Consumer participation in the planning and delivery of drug treatment services: The current arrangements. *Drug and Alcohol Review*, 27, 130-137.
- Bryant, J., Saxton, M., Madden, A., Bath, N. & Robinson, S. 2008b. Consumers' and providers' perspectives about consumer participation in drug treatment services: Is there support to do more? What are the obstacles? *Drug and Alcohol Review*, 27, 138-144.
- Crawford, S. 2013. Shouting through bullet-proof glass: some reflections on pharmacotherapy provision in one Australian clinic. *International Journal on Drug Policy*, 24, e14-7.
- Critical Appraisal Skills Programme (CASP). 2014. *CASP Checklists* [Online]. Oxford: CASP. Available: <http://www.casp-uk.net/checklists> [Accessed 25th July, 2016 2014].
- Davidson, L. 2016. The Recovery Movement: Implications For Mental Health Care And Enabling People To Participate Fully In Life. *Health Affairs*, 35, 1091-1097.
- Dawson, A. J., Nkowane, A. M. & Whelan, A. 2015. Approaches to improving the contribution of the nursing and midwifery workforce to increasing universal access to primary health care for vulnerable populations: a systematic review. *Human Resources for Health*, 13, 97.
- Doughty, C. & Tse, S. 2011. Can consumer-led mental health services be equally effective? An integrative review of CLMH services in high-income countries. *Community Mental Health Journal*, 47, 252-66.



Granfield, R. & Cloud, W. 2001. Social Context and "Natural Recovery": The Role of Social Capital in the Resolution of Drug-Associated Problems. *Substance Use and Misuse*, 36, 1543-1570.

Greer, A. M., Luchenski, S. A., Amlani, A. A., Lacroix, K., Burmeister, C. & Buxton, J. A. 2016. Peer engagement in harm reduction strategies and services: A critical case study and evaluation framework from British Columbia, Canada. *BMC Public Health*, 16.

Harris, J. & McElrath, K. 2012. Methadone as social control: institutionalized stigma and the prospect of recovery. *Qualitative Health Research*, 22, 810-24.

Hinton, T. 2010. *Voices on choices : working towards consumer -led alcohol and drug treatment*. 2010. Tasmania, Anglicare Social Action Research Centre.

Hyshka, E., Karekezi, K., Tan, B., Slater, L. G., Jahrig, J. & Wild, T. C. 2017. The role of consumer perspectives in estimating population need for substance use services: a scoping review. *BMC Health Services Research*, 17.

Institute of Medicine 2001. *Crossing the quality chasm: a new health system for the 21st Century*, Washington DC, National Academic Press (US).

Joanna Briggs Institute. 2017. *Checklist for Analytical Cross Sectional Studies* [Online]. Available: [http://joannabriggs.org/assets/docs/critical-appraisal-tools/JBI\\_Critical\\_Appraisal-Checklist\\_for\\_Analytical\\_Cross\\_Sectional\\_Studies2017.pdf](http://joannabriggs.org/assets/docs/critical-appraisal-tools/JBI_Critical_Appraisal-Checklist_for_Analytical_Cross_Sectional_Studies2017.pdf) [Accessed 25th April 2017].

King, A. 2011. Service user involvement in methadone maintenance programmes: The 'philosophy, the ideal and the reality'. *Drugs: Education, Prevention, and Policy*, 18, 276-284.

Kumar, P. C., Mcneely, J. & Latkin, C. A. 2016. "It's Not What You Know but Who You Know": Role of Social Capital in Predicting Risky Injection Drug Use Behavior in a Sample of People who Inject Drugs in Baltimore City. *Journal of Substance Use and Misuse*, 21, 620-626.

Lancaster, K., Seear, K., Treloar, C. & Ritter, A. 2017. The productive techniques and constitutive effects of 'evidence-based policy' and 'consumer participation' discourses in health policy processes. *Social Science and Medicine*, 176, 60-68.

Leppo, A. & Perala, R. 2009. User involvement in finland: The hybrid of control and emancipation. *Journal of Health, Organisation and Management*, 23, 359-371.

Meehan, T. J., King, R. J., Beavis, P. H. & Robinson, J. D. 2008. Recovery-based practice: Do we know what we mean or mean what we know? *Australian and New Zealand Journal of Psychiatry*, 42, 177-182.

- Nathan, P. E., Conrad, M. & Skinstad, A. H. 2016. History of the Concept of Addiction. *Annual Review Clinical Psychology*, 12, 29-51.
- National Registry of Evidence-Based Programs and Practices. 2009. *Brief Strengths-Based Case Management for Substance Abuse* [Online]. Available: <https://www.nrepp.samhsa.gov/Legacy/ViewIntervention.aspx?id=58> [Accessed 14<sup>th</sup> March 2018].
- NDTMS 2016. Reference Data Core Dataset N. London: National Drug Treatment Monitoring System, Public Health England.
- Norrish, A., Biller-Andorno, N., Ryan, P. & Lee, T. H. 2013. *Building Social Capital as a Strategy to Improve Healthcare Performance* [Online]. Harvard Business Review. Available: <https://hbr.org/2013/11/social-capital-is-as-important-as-financial-capital-in-health-care?autocomplete=true> [Accessed 14<sup>th</sup> March 2018].
- Panebianco, D., Gallupe, O., Carrington, P. J. & Colozzi, I. 2016. Personal support networks, social capital, and risk of relapse among individuals treated for substance use issues. *International Journal on Drug Policy*, 27, 146-53.
- Patterson, S., Weaver, T., Agath, K., Albert, E., Rhodes, T., Rutter, D. & Crawford, M. 2009a. 'They can't solve the problem without us': a qualitative study of stakeholder perspectives on user involvement in drug treatment services in England. *Health and Social Care in the Community*, 17, 54-62.
- Patterson, S., Weaver, T., Agath, K., Rutter, D., Albert, E. & Crawford, M. J. 2009b. User involvement in efforts to improve the quality of drug misuse services in England: A national survey. *Drugs: Education, Prevention, and Policy*, 16, 364-377.
- Patterson, S., Weaver, T. & Crawford, M. 2010. Drug service user groups: Only a partial solution to the problem of developing user involvement. *Drugs: Education, Prevention, and Policy*, 17, 84-97.
- Public Health England 2015. Service user involvement a guide for drug and alcohol commissioners providers and service users. London: Public Health England.
- Putman, R. 1993. *Making democracy work; civic traditions in modern Italy*. Princeton NJ, Princeton University Press.
- Radcliffe, P. & Stevens, A. 2008. Are drug treatment services only for 'thieving junkie scumbags'? Drug users and the management of stigmatised identities. *Social Science & Medicine*, 67, 1065-73.
- Rance, J. & Treloar, C. 2015. "We are people too": Consumer participation and the potential transformation of therapeutic relations within drug treatment. *International Journal of Drug Policy*, 26, 30-36.
- Rapp, C. A. & Goscha, R. J. 2011. *The Strengths Model. A Recovery Orientated Approach to Mental Health Services*, New York, Oxford University Press.
- Roussy, V., Thomacos, N., Rudd, A. & Crockett, B. 2015. Enhancing health-care workers' understanding and thinking about people living with co-occurring mental

health and substance use issues through consumer-led training. *Health Expectations*, 18, 1567-81.

Schulte, S., Moring, J., Meier, P. S. & Barrowclough, C. 2007. User involvement and desired service developments in drug treatment: Service user and provider views. *Drugs: Education, Prevention, and Policy*, 14, 277-287.

Shea, B., Santesso, N., Qualman, A., Heiberg, T., Leong, A., Judd, M., Robinson, V., Wells, G. & Tugwell, P. 2005. Consumer-driven health care: Building partnerships in research. *Health Expectations*, 8, 352-359.

Siegal, H. A., Rapp, R. C., Kelliher, C. W., Fisher, J. H., Wagner, J. H. & Cole, P. A. 1995. The strengths perspective of case management: a promising inpatient substance abuse treatment enhancement. *Journal of Psychoactive Drugs*, 27, 67-72.

Simpson, E., L & House, A., O 2002. Involving users in the delivery and evaluations of mental health services: systematic review. *The BMJ*, 325, 1265-1270.

Tambuyzer, E., Pieters, G. & Van Audenhove, C. 2014. Patient involvement in mental health care: one size does not fit all. *Health Expectations*, 17, 138-50.

The Royal Australian and New Zealand College of Psychiatrists. 2012. *Mental Health for the Community. Principles to Underpin effective Mental Health Service Delivery to the Community* [Online]. Available:

[https://www.ranzcp.org/Files/Resources/College\\_Statements/Position\\_Statements/p573-pdf.aspx](https://www.ranzcp.org/Files/Resources/College_Statements/Position_Statements/p573-pdf.aspx) [Accessed 16th November 2016].

Ti, L., Tzemis, D. & Buxton, J. A. 2012. Engaging people who use drugs in policy and program development: A review of the literature. *Substance Abuse: Treatment, Prevention, and Policy*, 7.

Tober, G., Raistrick, D., Fiona Crosby, H., Sweetman, J., Unsworth, S., Suna, L. & Copello, A. 2013. Co-producing addiction aftercare. *Drugs and Alcohol Today*, 13, 225-233.

Tomes, N. 2006. The patient as a policy factor: a historical case study of the consumer/survivor movement in mental health. *Health Affairs*, 25, 720-9.

Treloar, C., Rance, J., Madden, A. & Liebelt, L. 2011. Evaluation of consumer participation demonstration projects in five Australian drug user treatment facilities: the impact of individual versus organizational stability in determining project progress. *Substance Use and Misuse*, 46, 969-79.

Tritter, J. Q. & McCallum, A. 2006. The snakes and ladders of user involvement: Moving beyond Arnstein. *Health Policy*, 76, 156-68.

Trujols, J., Iraurgi, I., Oviedo-Joekes, E. & Guardia-Olmos, J. 2014. A critical analysis of user satisfaction surveys in addiction services: opioid maintenance treatment as a representative case study. *Patient Preference and Adherence*, 8, 107-17.

Van Hout, M. C. & Mcelrath, K. 2012. Service user involvement in drug treatment programmes: Barriers to implementation and potential benefits for client recovery. *Drugs: Education, Prevention and Policy*, 19, 474-483.

Weston, S., Honor, S. & Best, D. 2018. A Tale of Two Towns: A Comparative Study Exploring the Possibilities and Pitfalls of Social Capital among People Seeking Recovery from Substance Misuse. *Substance Use and Misuse*, 53, 490-500.

Who. 1978. *Declaration of Alma-Ata* [Online]. Europe. Available: file:///E:/E93944.pdf [Accessed 2nd May 2016].

Woolcock, M. 2001. The place of social capital in understanding social and economic outcomes. *Isuma: Canadian Journal of Policy Research*, 2, 11 -17.

Wylie, L. W. J. 2010. Assessing user perceptions of staff training requirements in the substance use workforce: A review of the literature. *Drugs: Education, Prevention, and Policy*, 17, 618-631.

Zoorob, M. J. & Salemi, J. L. 2017. Bowling alone, dying together: The role of social capital in mitigating the drug overdose epidemic in the United States. *Drug and Alcohol Dependence*, 173, 1-9.

