



## Research paper

# “We are people too”: Consumer participation and the potential transformation of therapeutic relations within drug treatment



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## ARTICLE INFO

## Article history:

Received 5 February 2014

Received in revised form 5 May 2014

Accepted 7 May 2014

## Keywords:

Consumer participation  
Drug use and treatment  
Stigma and discrimination  
Service users and providers  
Qualitative interviews  
Australia

## ABSTRACT

**Background:** While there is growing recognition of the benefits of user involvement within drug treatment there is scant literature documenting the actual implementation of such initiatives. Nonetheless, the extant research is remarkably consistent in identifying poor relationships between service users and staff as a principal barrier to the successful implementation of consumer participation. Focussing on participants' accounts of change within the 'therapeutic alliance', this paper investigates a consumer participation initiative introduced within three Australian drug treatment services.

**Methods:** In 2012, the New South Wales Users and AIDS Association (NUAA), a state-based drug user organisation, introduced a consumer participation initiative within three treatment facilities across the state. This paper draws on 57 semi-structured interviews with staff and service-user project participants. Approximately ten participants from each site were recruited and interviewed at baseline and six months later at evaluation.

**Results:** The enhanced opportunities for interaction enabled by the consumer participation initiative fostered a sense of service users and staff coming to know one another beyond the usual constraints and limitations of their relationship. Both sets of participants described a diminution of adversarial relations: an unsettling of the 'them and us' treatment divide. The routine separation of users and staff was challenged by the emergence of a more collaborative ethos of 'working together'. Participants noted 'seeing' one another – *the other* – differently; as people rather than simply an identity category.

**Conclusion:** For service users, the opportunity to have 'a voice' began to disrupt the routine objectification or dehumanisation that consistently, if unintentionally, characterise the treatment experience. Having a voice, it seemed, was synonymous with *being human*, with having ones' 'humanness' recognised. We contend that not only did the introduction of consumer participation appear to empower service users and enhance the therapeutic alliance, it may have also improved service quality and health outcomes.

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## Introduction: the rise of 'consumer participation'

Over the past three decades, Western liberal democracies have witnessed the widespread emergence of 'consumer participation': the notion of service-user involvement in public policy-making and service delivery (Crawford et al., 2002; Ti, Tzemis, & Buxton, 2012; Tritter & McCallum, 2006). The language of *user involvement, empowerment and participation* has become 'ubiquitous in healthcare discourse' (Patterson et al., 2008, p. 54). In Australia too, consumer participation has become a key principle in the delivery of health and social welfare services (Hinton, 2010, p. 9; see also Nathan, 2004). Here national health policy broadly defines consumer participation as, 'the process of involving health consumers

in decision-making about health service planning, policy development, setting priorities and quality issues in the delivery of health services' (Commonwealth Department of Health and Aged Care, 1998). The Australian Commission on Safety and Quality in Healthcare currently lists 'partnering with consumers' as number two on its checklist of ten key principles or 'standards' (Australian Commission on Safety and Quality in Health Care, 2011, p. 22).

Nonetheless, despite its commonplace occurrence in areas of healthcare such as mental health, disability and cancer treatment (Hinton, 2010, p. 9), the introduction of consumer participation within the Australian drug treatment field has lagged conspicuously behind (Hinton, 2010; Treloar, Rance, Madden, & Liebelt, 2011). While the current National Drug Strategy (Ministerial Council on Drug Strategy, 2011) advocates 'consumer participation in governance' (p. 3) as part of its broad commitment to harm minimisation (alongside promoting a national approach to user involvement that includes quality frameworks and reporting

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requirements) there remains ‘virtually no evidence of policy frameworks specifically developed to support consumer participation in the drug user treatment context’ (Treloar et al., 2011, p. 2). Recent studies by Australian research teams (Bryant, Saxton, Madden, Bath, & Robinson, 2008; Bryant, Saxton, Madden, Bath, & Robinson, 2008) found that while consumer participation activities in drug treatment settings were not uncommon – in fact were widely endorsed ‘in-principle’ by both consumers and providers – they were primarily restricted to low level involvement (suggestion boxes and so forth); were largely ineffectual due to ‘poor communication between providers and consumers’ (Bryant et al., 2008a, p. 130); and that ‘a significant shortcoming exists with respect to turning this in-principle commitment into practice’ (p. 136).

### Our approach: the drug treatment setting

Appreciating the unique complexities of consumer participation within drug treatment is hampered by a dearth of Australian and international research (Hinton, 2010; Neale, 2006; Ti et al., 2012; Treloar et al., 2011). While there has been growing recognition of the benefits of user involvement there is scant literature documenting the actual implementation of such initiatives (Fischer & Neale, 2008; Neale, 2006; Ti et al., 2012). Nonetheless, the extant research has been remarkably consistent in not only underscoring the actual and/or potential benefits of consumer participation in drug treatment but in identifying the very particular challenges it faces. The deleterious impact of stigma, discrimination and unequal service-user–staff relations has been highlighted repeatedly (Fischer & Neale, 2008; Hinton, 2010; Patterson et al., 2008, 2009; Patterson, Weaver, & Crawford, 2010; Ti et al., 2012; Treloar et al., 2011). Patterson et al. (2008) describe the drug treatment setting as a ‘complex cultural context imbued with stigma’ (p. 60); one where power imbalances and prejudices are ‘invidious’ and ‘a pervasive influence’ on user involvement (p. 59). Many service staff continues to hold ‘deep stereotypes’ (Zibbell, 2004, p. 62) about people who inject drugs, leading to discriminatory practices in service provision. Underpinning this stereotype is what Treloar and Holt (2006) describe as a ‘deficit model’: ‘The perception of a person seeking drug treatment . . . as deficient, defective or lacking’ (p. 377). Or, as Crawford (2013) puts it from the perspective of consumers: ‘[r]egardless of whether we are seen as immoral or sick we are understood as a problem to be solved’ (p. e15). The potential of the therapeutic alliance is all-too-frequently reduced to an ‘us and them’ scenario, characterised by ‘mutual antagonism’ (McDermott, 2002, p. 18) and exacerbated by the structural inequalities underpinning the relationship between users and services (Patterson et al., 2008; Treloar et al., 2011; Zibbell, 2004).

This paper takes up the question of the ‘therapeutic alliance’ via an investigation of a consumer participation initiative – the CHANGE Project – introduced within three Australian drug treatment settings. Our intention here is not to produce a comprehensive nor ‘balanced’ review of the project. Rather, by analysing interviews with service users and staff and capturing the shifts in interpersonal dynamics between the two we hope to elucidate the conditions under which something new was produced. While our focus is on those aspects of the intervention that ‘worked’ – that effected change – we do not want to present an unrealistically rosy picture of wholesale transformation. In important respects our findings are noteworthy precisely because of considerable barriers that militate against the successful introduction of consumer participation within drug treatment. As noted above, one of the chief barriers consistently cited in the literature is the relationship between service users and staff. Hence our focus on evidence of change within that dynamic – evidence found within accounts from

both service-user and staff participants of the CHANGE Project. What made such transformation possible?

### The drug-using subject and the notion of ‘epistemic injustice’

Elsewhere we have argued that the meanings attached to drug treatment service users – their treatment identities – ‘both reflect and participate in the limited and limiting repertoire of socially available and invariably stigmatising interpretations of the ‘drug user’ (Rance, Newland, Hopwood, & Treloar, 2012, p. 249). Central to these ‘stigmatising interpretations’ is the disregard and disqualification with which the drug-using subject is routinely treated. Within opioid substitution therapy (OST), for instance – the most popular and populous of Australian drug treatment modalities – service users are commonly viewed as not merely consumers, or customers, but as ‘inherently dishonest drug users’ (Fraser & Valentine, 2008, p. 123). Or, as Crawford puts it: ‘[w]e pay money like a customer but are generally treated like a naughty patient’ (2013, p. e15).

The suspicion and disregard with which they are treated – their ‘credibility deficit’ (Fricker, 2007) – has profound implications for service users. What is at issue is the questioning, the doubting, of drug users’ capacity to reason and make decisions (Wolfe, 2007), to be fully rational subjects (Seear et al., 2012) and ultimately, by extension, their very membership of the human community (Moore & Fraser, 2006). What Manderson (2011) refers to as their ‘absolute otherness’ (p. 230). Here the work of philosopher Miranda Fricker (2007) is particularly illuminating. Fricker uses the term ‘epistemic injustice’ to describe a form of injustice that takes place when social prejudice undermines the level of credibility ascribed to certain speakers: a process by which particular social subjects are undermined specifically in their capacity to know and share knowledge. Fricker argues that our capacity to pass on knowledge is not only intimately bound up with our status as rational beings, but ultimately, as human beings. Thus, she argues, to be undermined in one’s capacity as a ‘knower’ is to be ‘wronged in a capacity essential to human value (p. 44). Epistemic injustice then, according to Fricker, is not only about being degraded as a knower but about the *meaning* of being treated like that. It carries a symbolic power that adds its own layer of harm: ‘a social *meaning* to the effect that the subject is less than fully human . . . a dehumanizing meaning’ (p. 44).

### Method

In 2012, the NSW Users and AIDS Association (NUAA), a state-based drug user organisation, was contracted by the New South Wales (NSW) Ministry of Health to undertake consumer participation projects in three drug treatment facilities across the state: two publicly-funded opiate substitution therapy (OST) services and one non-government residential rehabilitation service. The Centre for Social Research in Health (CSRH) was employed by NUAA to evaluate what became known as ‘The CHANGE Project’. The initiative introduced a range of activities or ‘objectives’ across the different sites: a ‘welcome diary’ for new residents, a service-users’ newsletter, a policy review committee, tea and information stalls, etc. The choice of activities at each location was determined by service users in collaboration with the NUAA project worker. In addition, NUAA coordinated a three-day workshop (the Consumer Participation Training package) at each clinic; service users and staff attending one day each before uniting for the final day.

Over the six months following the workshop, service users from each of the three clinics worked in collaboration with the NUAA project coordinator to initiate a series of consumer participation

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