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The value of involvement from the perspective of service users and carers engaged in practitioner education: Not just a cash nexus

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SUMMARY

This paper presents qualitative findings emergent from a participatory action research (PAR) study focused on developing service user and carer involvement in a university setting. The involvement of these experts by experience in practitioner education for health and social care, and nursing in particular, is now an international phenomenon. Adhering to the philosophy and practices of PAR, the project and the writing of this paper have been collectively produced. Data has been organised using simple thematic analysis into three broad themes accounting for different ways in which participating service users and carers obtain a sense of value from their involvement. We have titled these themes: a more positive sense of self; social and relational benefits; altruism in activism. Drawing on these participant narratives we develop an understanding of the relationship between involvement and reward that does not simply reflect value in payment.

Introduction

The terms service user and carer are not uncontested (see Beresford, 2005; McKeown et al., 2010 for more detailed discussion of definitional problems) and refer to different groups who might have a stake in the quality of both practitioner education and wider services. In this paper we refer to a project that involves service users and carers, but respects that these groups are heterogeneous and will on occasion hold different or even oppositional views. We assert that the teaching and learning of practitioners are enhanced by the involvement of both service users and carers, however defined. Whilst the extensiveness, quality, or experience may vary, service user and carer involvement in universities is now an accepted part of the education of nurses and other practitioner groups in a range of international contexts (see Wykurz and Kelly, 2002; Happell et al., 2002; Felton and Stickley, 2004; Warne and McAndrew, 2004; Basset et al., 2006; Beresford et al., 2006; Lathlean et al., 2006; Repper and Breeze, 2007; Brown and Young, 2008; Towle et al., 2010; McKeown et al., 2010). Certain institutions have gone so far as to appoint service users to academic posts (Happell et al., 2002; Simons et al., 2007). Similarly, the desirability of service user involvement in knowledge production and research partnerships (see Church, 2005; Hanley, 2005; Involve, 2007; Frankham, 2009) is so well-established that its presence is typically assessed as part of the grant approval process.

These developments can be seen as part of a broader trend of State interest (at least rhetorically) in public involvement in the UK (DH, 2004, 2005, HM Government, 2007) and globally (World Health Organisation, 1990). Contradictory ideologies of consumerism clash with the politics of social movements in opening up opportunities for involvement and participation (Crossley, 2006; Spandler, 2006; Brown and Zavetoski, 2005; Williamson, 2008). Such tensions can be seen to be reflected in the varying dispositions towards payment for involvement in the research findings presented here.

The extent to which such involvement can transcend tokenistic forms and aspire to greater authenticity of expression or achieve genuine empowerment, autonomy or control for participants are perennial concerns, leading to efforts at evaluation which locate and value different levels of participation (Arnstein, 1969; Tew et al., 2004; Tritter and McCallum, 2006). Commentators such as Stickley (2006), Cowden and Singh (2007), Beresford (2002) and Pilgrim (2005) have variously questioned the extent to which service users' transformative goals are best served within prevailing institutionalised or incorporated processes. The academic setting, being somewhat removed from the arenas of statutory power or clinical practice, exemplifies, perhaps fortuitously, a privileged space for enacting involvement (McKeown et al., 2010). Whilst incorporation and co-option threats persist, there are perhaps greater opportunities for trust to be established and nurtured. Nonetheless, it must be

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acknowledged that various university systems, especially with regard to the management of finance and resource allocation, are problematic and impact upon the practice of involvement.

The contemporary public sphere is replete with commentary on value: private goods and markets are driven by the sense of value expressed as price or labour value expressed in wages, and public goods and amenities are becoming ever more subject to market principles allegedly aimed at improving value for money (Gubb and Meller-Herbert, 2009). In all of these examples, the idea of value is a proxy for forms of reward, though not all human activity is neatly commensurate with the idea of value expressed in monetary terms (Kuttner, 1999). For example, most cultures have a lengthy tradition of volunteerism, whereby work is undertaken for the benefit of others without remuneration (Smith, 1981).

The aim of the research presented here was to explore the value of involvement from the perspective of service user and carer participants involved in the education of health and social care practitioners in a university setting. This focus is selective; without dismissing the importance of any contribution we are not concerned in this paper with the views of participating staff, for instance those who initiated and supported the involvement activity.

Findings are presented from data collection undertaken in the course of establishing and sustaining one model of involvement in a university: the Comensus initiative. This initiative is known for the extensiveness and plurality of user and carer involvement that is supported and is probably unique amongst UK universities with regard to the range of courses and professional disciplines covered. Comensus employs a full-time co-ordinator (Malihi-Shoja) and a part time administrative assistant and is supported by a number of key academic staff; indeed the quality of support and solidarity has been commented upon by participating service users and carers (Downe et al., 2007; McKeown et al., 2010).

Comensus began in 2004 with a remit to explore, formulate, and put into practice a systematic approach to supporting service user and carer involvement across the then Faculty of Health and Social Care in the University of Central Lancashire (Appendix A, electronic version). Opportunities for involvement span all aspects of teaching, research, and strategic decision making (McKeown et al., 2010). There are examples of service user and carer involvement across all these domains at all levels, but this does not mean that such involvement is absolutely comprehensive and any participant may be involved to a greater or lesser degree than other peers. Contributions to teaching and learning cover the range of practitioner groups taught at the university with the majority relating to nursing and social work. The pre-qualifying social work course (BA and MA) includes a user-led module, developed by service users and carers, taught by them, and assessed by them — marking student essays with support and moderation provided by academic staff. The service user and carer contribution has been subject to review by various relevant regulatory bodies (Nursing and Midwifery Council (NMC), General Social Care Council (GSCC), higher education Quality Assurance Agency (QAA)), who have invariably commented positively on these developments.

Service user involvement brings numerous benefits for universities, for example, improving relationships with local communities, enhancing reputation for quality and generating income (Appendix B, electronic version). There has been relatively little consideration of issues of value from the service user or carer perspective. What published work there is largely attends to issues of monetary value and the vexed issue of remuneration for involvement. Numerous guidelines, position papers and commentary have been published on this topic, but this is not our primary focus here. Whilst the politics and practices of payment are immensely important (DH, 2006), the findings discussed here suggest that service user and carer identifications of value are more complex than can be reduced to singularly materialistic or instrumental concerns.

Method

Participatory Action Research (PAR)

The Comensus initiative was framed as a modified PAR study (Reason and Bradbury, 2000; Kemmis and McTaggart, 2003), comprising iterative cycles of planning–action–observation–reflection–planning (Lewin, 1946). Development practices are indivisible from inquiry and usual boundaries between researcher and researched are blurred. This methodology can be associated with critical social theory, offering possibilities for democratising research with emancipatory effects for participants. Ours was a modified form as a planning stage to secure funding was largely led by university personnel; though this was informed by previous engagement with community partners. From that point onwards we intended the process to be as authentically participatory as possible. The approach primarily focuses on change in the setting where the action takes place. Despite this, theoretical insights emerging from our analysis may be cautiously applicable elsewhere in similar contexts.

We consider the overarching study, and hence the development of Comensus, to be divisible into a number of meta-cycles or phases (for a more detailed account of this see Downe et al., 2007; McKeown et al., 2010). Each meta-cycle involves a number of micro-cycles of the action research process. Broadly speaking the project has progressed through three of these phases to date: First (January 2004–February 2005), the period setting up and launching the project, listening and liaising with community partners, leading to the recruitment of the first Community Involvement Team (CIT); a diverse team of 21 members with different forms of service use or carer experiences, who engage strategically with the University and are responsible for guiding and developing the initiative. Second (March 2005–June 2006), the period spanning the establishment, formation and maturation of the CIT. The CIT can be seen as the decision making forum within Comensus. They are linked to scores of affiliated community groups and nearly 200 wider community members who are available to respond to specific requests for involvement that match their personal experience. Third, the current phase, spanning 2006 to the present, which is typified by efforts to promote the independence of the CIT and increasingly autonomous practices led by service users and carers. This has also involved developing systems to refresh the membership of the CIT, introducing new peer mentorship roles for some.

Ethical approval was sought and obtained from UCLan Faculty of Health Research Ethics Committee.

Data Collection, Analysis and Reporting

In an action research project almost everything which takes place or is produced in action is data. For us this includes meeting notes, actions and observations, reflective diaries, formal reports, talk between participants, recorded interviews and focus groups. In the first phase of the project we had funding to employ a research assistant, who made field notes and regularly debriefed or interviewed participating service users, carers and staff. Initial data explored participants' motivations to take part and views on payment and other forms of value.

In the later phases we have continued to build into our work intervals for reflection including annual debriefings of individual participants. Hence, there has been a continuous process of asking ourselves what is happening, how do we make sense of it, what are our priorities, how do we feel about key issues, what motivates us to carry on, what could be done better and how? We write reports and scholarly papers as collectively as possible, and have just produced a book in this style (McKeown et al., 2010). This writing mirrors the PAR approach, involving cycles of collective reflection, writing, review and redrafting. The data presented in this paper is drawn from views