

Editorial: Measuring Consumer Involvement in Health and Social Care: Dividing Fact from Fiction

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After the success of last year's special issue on Consumer, User and Carer Involvement in Health and Social Care, it is both a pleasure and a privilege to be invited to edit this mini special issue relating once more to the involvement of consumers in health and social care including health and social care research.

It is likely that we will all, at some stage or another, become recipients of care. How much influence we have over the care we receive will vary, but the likelihood of having meaningful involvement decreases as our vulnerability and neediness become greater. Poor standards of care are evident around the world, but only a small number of cases of poor or neglectful care are ever publicised and challenged. No one would wish such care on either themselves, those close to them, or indeed anyone in need of medical care or social support. Consumer involvement (or patient and public involvement as it is more commonly referred to in the United Kingdom) presents an opportunity to increase health and social care standards worldwide, and could even challenge and stamp out many of the poor or neglectful practices that currently take place. Sadly, examples of true involvement where the consumer has both the power and authority to instigate change are rare. Many things stand in their way, not least, the lack of clear identification of what constitutes 'meaningful' consumer involvement from a consumer perspective i.e. consumer involvement that goes beyond the many activities that purport to involve the consumer and are no more than mere window dressing. As we begin to be more discerning in our consideration of what is and is not valid consumer involvement, the identification of appropriate measures of involvement, and the measurement of their effects, are issues which must be taken more seriously.

With this in mind, the theme of this special mini issue concerns the measurement of consumer involvement in health and social care (including research) and offers opinions on whether such involvement can indeed be measured, and, if so, how this might be achieved. Perhaps because of the rather specialist nature of this focus, the initial call for papers resulted in a worthwhile, but somewhat restricted, response; the vast majority of submissions coming from the UK with a very limited number of international papers. The one American paper included in this issue demonstrates real concerns regarding changes in the health care system in the USA and, while focusing less on the actual measurement of involvement, highlights the consequences of lack of public consultation surrounding health and social care.

Parallel with the American experience, there is much current publicity surrounding proposed changes to the National Health Service in England. Despite this, the UK papers reflect a very live enthusiasm and determination to prove the usefulness and efficacy

of involving consumers in their health and social care through stringent and effective measurement. Purtell and Wyatt offer a useful starting point by arguing that, before there can be effective measurement of consumer involvement, there must be a clear articulation of its value and purpose. They suggest that, without a clear notion of the aims and intentions, it is not possible to measure either the success or the impact of involvement. Clearly, before researchers, commissioners and policy makers begin any health and social care research they must be explicit about who will be served by involvement and outline the criteria (and time frame) for measuring the impact of consumer involvement in the research process. Barber *et al* continue this theme by suggesting that it is not only the outcome of consumer involvement that is important but exploration of the process is essential to understanding how, when, why and if involvement works. They offer an example of a study in which regular reflective discussions were held about the process and progress of consumer (i.e. service user) involvement and suggest that such deliberations enhance working relationships between researchers and consumers as well as offering a valuable means of understanding the benefits of such involvement.

Lloyd and Carson move from involvement in research to the involvement of consumers of mental health services in their own care. They argue that compassionate care within mental health services is vital and that, despite the widely held view that compassion is intangible, it can be measured. Evidence should be provided in the case notes of service users of equal recognition between consumers and practitioners, of ongoing consumer views as to their progress toward recovery and of equal recognition of the stories of consumers and practitioners. This would demonstrate authentic consumer involvement and supply proof of compassionate care.

Neither compassion nor involvement feature large in Kover's article which considers healthcare in the United States (US) for 'vulnerable' people. He demonstrates how some people can become 'disposable' in society. Moving beyond description and using experimental design, Kover attempts to probe deeper into the minds of such people in an attempt to understand their thoughts. He argues that they become (and inevitably perceive themselves to be) an unwanted and invisible minority with minimal access to the US healthcare system. Such 'disposable' people stand little chance of exerting any pressure to change the current system that fails them so miserably. This is unlikely to change because they lack any significant involvement or impact on the current healthcare system. The article provides a very vivid illustration of the possible negative consequences when consumers and the public are not consulted about their health and social care.

The impact of consumer involvement is possibly one of its most important and most considered aspects. The article by Staniszkowska *et al* addresses this and concludes the discussions around the measurement of consumer involvement by arguing that, although there is little doubt that involvement is necessary and has progressed satisfactorily, measurement of its impact is poorly defined and understood. They suggest that now is the time for robust measurement of the impact of involvement with consumers fully involved in the conceptualisation, theorisation and development of instruments for this purpose. Whilst acknowledging the importance of qualitative, usually retrospective, data in this context, they assert that strongly constructed, collaborative, quantitative measurement of the impact of consumer involvement is not only possible but vital. It will enhance our understanding of the difference that involvement makes to research findings and thus will demonstrate its benefit for all concerned.

In the previous special issue of the Journal devoted to consumer involvement in health and social care (Vol.34.5, September 2010), we proposed that genuine consumer involvement in health and

social care is a necessary prerequisite to the delivery of efficient, cost-effective, consumer centred provision. In this issue we have set out to demonstrate that it is necessary and possible to measure the effectiveness of consumer involvement in achieving these aims. Undoubtedly, what is currently missing from the consumer involvement landscape (in both quality and quantity) is evidence of the impact of consumer involvement within health and social care systems. Attempts should now be made to design a substantial programme of research that sets out to systematically measure the impact of consumer involvement in health and social care both nationally and internationally.

Christine Wilson
Research Fellow,
University of Glamorgan
Dr. Penny Llewellyn
Senior lecturer (retired)
Howard Moskowitz
President Moskowitz Jacobs Inc.