

A5 Involving consumers – the rules of engagement

Leader/s: Andrew Corbett-Nolan

Objectives/rationale:

“the service user is the most valuable resource in healthcare”

Rightly, the benefits to involving patients and carers in the design, delivery and review of health and social care services has become an issue in efforts to improve the quality of care. However, often this involvement is paternalistic, unrealistic and poorly managed. Service users can be left feeling taken for granted, not listened to and disempowered by the experience. Equally often, services have not thought through what help they want from users or how to use this input.

The Health and Social Care Quality Centre is developing rules of engagement for service users, and would like to run a workshop at the ISQua conference as part of this development process to both tell the story of their approach to user involvement and to test whether (and how) these rules of engagement can be useful to the international quality community. The rules of engagement are being developed by service users who are in themselves expert patients, drawing on both personal experience of being involved as patients with the planning, delivery and review of health and social care services as well as some of the research into this area. Much of this experience is from the fields of older people's care, mental health and HIV care where user involvement is perhaps most advanced across the range of healthcare specialties.

The aims of the session are:

- Inform participants about this development work and involve them in it's refinement
- Test whether this tool could be useful internationally, and if so what local refinements would it need
- Critically examine best practice from the fields of older people's care, mental health and HIV care
- Challenge healthcare quality specialists to consider why, on what basis and how meaningfully they involve service users in the design, operation and review of care services

The structure of the session would be:

25% – outlining the issues and presenting the Health and Social Care Quality Centre draft rules of engagement, telling the story behind and of their development

25% – group work to critically examine the rules of engagement, with the tasks of identifying refinements, aspects which would need to differ for application outside the United Kingdom and ways in which their application could be reviewed to identify the added value of their use

25% - feedback, questions etc from the above

25% - development of best practice guides/maturity matrix for the involvement of user involvement templates, which could be the rules of engagement or any other similar template

Session leaders

Andrew Corbett-Nolan – Registrar, Secretary and founder of the Health and Social Care Quality Centre. Andrew has worked in healthcare quality since 1990, leading as national director of a national NHS clinical services accreditation unit, as a director of the King's Fund Health Quality Service and as founder of the Health and Social Care Quality Centre. He has been involved in voluntary organisations including as Vice Chair of the Terrence Higgins Trust, the largest HIV NGO in Europe. Andrew lives with a long term medical condition and has been involved in the quality improvement of his treatment centre.

Ian Kramer – a service user. Ian is also attached to the NHS Modernisation Agency, helping to advise and to train healthcare managers and quality improvement specialists. Before retiring from work on health grounds, Ian was a barrister at law and was a member of the Bar in both London and California. Ian has advised the department of Health as well as local NHS organisations on the development of care services

Martin Green – is chief executive of Counsel and Care, a national charity providing services and campaigning on behalf of older people. Martin is a Trustee of Age Concern, and has worked in user organisations throughout his career as well as being an advisor on issue relating to service users and carers to various Government Departments.