Service-user Involvement in Research

Consistent emphasis has been placed over recent years on the importance of service-user involvement in health care research by the Department of Health, research bodies and funding organisations. This participation has been validated further by government policy, believing that involving patients leads to more responsive services and better outcomes of care. The involvement of service-users in research is becoming paramount in today’s health care, with health policy indicating a change in direction from paternalistic approaches where professionals know best to a more consumerist environment where patient choice and opinion is vital. The need for this change in organisational culture is very clearly evident from the Francis report, with its graphic accounts of the shocking suffering experienced by patients and their families subjected to concealment and defensiveness.

Health care providers and university institutions of the future clearly need to be those that embrace more partnership with service-users and engage their experiences. Public involvement within institutions will need commitment and strategic approaches rather than tokenism or a ‘tick box’ mentality which may seem an easier option. Properly planned and integrated working with users can make a considerable demand on professional time, resources and budgets and this investment in time and energy is not automatically recognised always as ‘added value’, particularly by managers who may have more calculable ideas for their finances.

Good relationships with service-users requires negotiated agreement about options and responsibilities, with clear understanding as to where any power is located and where the user’s voice is heard, respected and influential. It seems pertinent at this point, however, to say that while involving the public in research undoubtedly can have significant impact, it can also lead to ‘colliding worlds’ (Faulkner, 2004), where the different perspectives of academic researchers and service-users can clash over certain priorities, concerns and outlooks.

Trying to develop and facilitate a research service-user group is not without its difficulties, the term ‘service-user’ itself, for example, infers a homogenous group of individuals from a variety of backgrounds and expectations, who are fundamentally representative of the populace they aim to stand for. However, while all are undoubtedly knowledgeable, motivated and eager to contribute, it is notoriously difficult to engage the socially excluded, those from ethnic minorities, with mental health problems or with learning disabilities, and yet it is the experiences and voices from these groups that need to be heard. Clearly, strategies need to be in place to attract and support such communities. When working in a research partnership with service-users or facilitating a research service-user group, it is also unrealistic to expect each lay member to automatically be able to understand academic jargon, research climates and cultures. Working in partnership with service-users inevitably involves training provision, good quality relationships and underpinning commitment and support.

The involvement of service-users in research and research groups is clearly more complex, multifaceted and far-reaching than may at first be suspected. Many challenges need to be overcome when attempting to embrace the concept of service-user involvement if the real benefits of service-users are to be determined and upheld. If there is no real commitment or insight from those who hold the purse strings then there is a danger that any attempt at service-user engagement will only become a desire or, more disturbingly, just political rhetoric.

Reference