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Developing a model to enhance patient involvement in designing and conducting research: Views of patients, academics and organisational staff

Helen Snooks, Evans B A, Porter A M, and Burholt V Swansea University Medical School, UK

Background: For patients to fully contribute their expertise to designing and conducting collaborative research, the interaction process with academic and organisational experts needs to be effective.

Objectives: To describe development and implementation of a model to enhance patient involvement in health and social care research.

Methods: Patients with chronic conditions were supported by a researcher to develop ways to enable their involvement in research about chronic conditions management. We explored experience of being involved in research through the model through interviews with participating patients, academics and senior managers responsible for health policy and services. Data were audio-recorded with consent and analysed using Interpretative Phenomenological Analysis.

Results: Patients established a pool structure, sharing support, information and skills development while available for recruitment to more than 30 collaborative research opportunities over three years. Interview respondents agreed the model increased the number and proficiency of patients involved in research. Academics and organisational managers perceived this was a credible and legitimate patient group. But recruitment and communication processes were confusing and interaction in research meetings was not consistently effective, they reported. Patients found the language and culture of research environments was off-putting and said they did not always know what they should and could contribute.

Conclusions: We developed a model which enhanced patients' contributory expertise and strengthened some interaction processes when they were involved in research through collaboration. Further research training for patients, improved communication and better ways to match patients' skills to research opportunities are needed to strengthen the model. Research teams should also clarify aims and roles of all collaborators when involving patients in research, to enable all expertise to be effectively integrated within research processes.

Biography

Helen Snooks is the Professor of Health Services Research in the Swansea University Medical School, UK. She is the Interim Director of the Swansea Trials Unit (STU) and leads the Patient and Population Health and Informatics (PPHI) research stream at Swansea University. Helen's main research interests and expertise lie in the fields of Emergency Pre-hospital and Unscheduled Care, Clinical Audit and Effectiveness, and research support. The focus of her work is to plan, design and carry out evaluations of health technologies and new models of service delivery. Helen has a Bsc (Hons) Economics, Sociology, Statistics from University of Surrey with a PhD in Health Services Research 'Post Traumatic Stress Disorder in seriously injured accident victims' at the University of Sheffield in 2000.

h.a.snooks@swansea.ac.uk

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