

P70

HOW CAN PATIENTS AND CARERS BE INVOLVED IN RESEARCH TO IMPROVE CARE? DEVELOPING AND EVALUATING A MODEL OF INVOLVEMENT

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¹A Evans, ¹H Snooks, ²David Rea, ³Service User Steering Group members. ¹*School of Medicine, Swansea University, Swansea, UK;* ²*School of Health Sciences, Swansea University, Swansea, UK;* ³*Chronic Conditions Management Service User Steering Group, Wales*

Objective To develop and evaluate a model to involve service users in researching impact of policy.

Design (a) a participative approach to develop an involvement model; (b) semi-structured interviews with service users (n=10) and researchers (n=2) to evaluate at 18 months.

Setting This project took place across Wales. Research was commissioned to assess impact of the new Chronic Conditions Management (CCM) policy. We wanted service users' knowledge and understanding to contribute to developing and implementing that research.

Participants Patients with chronic conditions and carers of people with chronic conditions.

Main Outcome Measure a) Service users participating in CCM research planning and management; b) Impact on research and participants.

Results 23 patients and carers were identified through two patient networks. Through workshops and discussions, they agreed an involvement model. This operated through a Steering Group providing support to service users and researchers. A flexible structure reflected unpredictable health status/ability to travel. Members

undertook research activities and attended research planning meetings. A structured reporting-back process ensured communication. Over 18 months, activity included: five Strategic research planning meetings with academics and policy makers; five Research management meetings; Research participation (qualitative analysis; data extraction; piloting questionnaires and interview schedules, dissemination); seven Steering Group meetings; and Acting as a forum connecting researchers and service users. Service users said the Steering Group gave them an identity and supported people's participation. Researchers said it allowed access to motivated service users. Researchers said service users changed their understanding of living with chronic illness. Service users wanted their involvement to have a positive impact on research but longer term participation was needed to enable this, they reported. Some thought they were bringing new perspectives to research. Being involved gave service users new confidence, skills, information and social opportunities. Sometimes it was challenging, tiring or frustrating. Travelling limited some people's participation. They were helped by feeling they had expertise and gaining a role to engage through. Working with service users gave researchers credibility because it offered insight into the experience of patients and carers. They also gained practice in involving service users in research.

Conclusion Patients and carers have experience and knowledge relevant to policy makers and researchers reviewing healthcare services. The model provides a mechanism linking these groups. Service users have fed their views into meetings covering project-specific and strategic topics from an early research stage. Service users and researchers benefited from co-researching. Longer term involvement is needed to identify full impact on research.