

# DEVELOPING A MODEL TO ENHANCE PATIENT INVOLVEMENT IN DESIGNING AND CONDUCTING RESEARCH: VIEWS OF PATIENTS, ACADEMICS AND MANAGERIAL STAFF

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## Background

Patients with chronic conditions are at high risk of using unscheduled and emergency services because health status fluctuates and deteriorates. We work with them to design and conduct collaborative research. We need an effective interaction process so patients can fully contribute their expertise and work alongside academic and managerial experts.

### Objectives

This poster describes how we developed and implemented a model to enhance patient involvement in health and social care research.

## Methods

### Developing the involvement model

Patients and carers with experience of managing chronic conditions were supported by a researcher to develop ways to enable their involvement in research about chronic conditions management. Through facilitated workshops and meetings, up to 16 patients and carers agreed core principles and ways of working to enable them to collaborate in research studies and activities.

### Assessing how the involvement model was implemented

We conducted interviews with three respondent groups. All had collaborated through the model:

- Patients and carers (n=20)
- Academics (n=4)
- Senior managers responsible for health policy and services (n=3)

Data were audio-recorded with consent, transcribed and analysed using Interpretative Phenomenological Analysis. This method focuses on capturing personal experiences using a structured, reflexive process designed to reveal complexity and interpret understandings in data.



## Results

### The model

Patients and carers named the model SUCCESS – Service Users with Chronic Conditions Encouraging Sensible Solutions.

They established a pool structure, sharing support, information and skills development through meetings and email contact. Time was set aside for reporting and discussing individual research experiences, gaining input from all members to inform contributions and widen the perspective brought to research activities. Researchers contacted the SUCCESS pool to recruit patients and carers.

SUCCESS members were involved in at least 200 research activities and projects over seven years, including:

- Research Management Group membership
- Trial Steering Committee membership
- Developing research bids
- Preparing data collection tools
- Undertaking analysis
- Writing abstracts
- Presenting at conferences

### Views on the model

Interview respondents all agreed the SUCCESS model increased the number and proficiency of patients and carers involved in research. They said the model brought together motivated people with relevant experience and ability to contribute to research decisions and tasks. Views and experiences were similar across respondent groups.

*It's enabled us to include service users when we wouldn't have been able to otherwise, without that pool being there (academic)*

Patients and carers felt the model provided a trustworthy channel to communicate their healthcare experiences. Academics and organisational managers perceived the SUCCESS pool was a credible and legitimate group to provide insight into patient and carer experience.

*It's a strength to know there's a group there. As an individual you could become lost, but as a group you have an identity (SUCCESS member)*

*The word to use is credibility. There was credibility of the people involved...it was having a group that was ready-made (health services manager)*

However, all respondents said interaction in research meetings was not consistently effective. Patients found language and culture of research environments was off-putting and said they did not always know what they should and could contribute. Although academics and managers reported greater awareness of patient perspectives, they said they did not always gain the information they sought and questioned whether SUCCESS members spoke as individuals or as patient representatives. All respondents considered the process of recruiting people from the SUCCESS pool and sharing research experience with the wider SUCCESS membership were confusing.

*Meetings, I don't think are necessarily the right forum...often those meetings aren't necessarily where their added value comes (academic)*

*It's nice to be involved but it's above our heads... particularly in the meetings in the university. It's your world – it's not our world (SUCCESS member)*



## Conclusions

We developed a model which enhanced patients' contributory expertise and strengthened some interaction processes when they were involved in research through collaboration.

However, all participants recognised that patients and carers could not always turn experience into the expertise which academic and managerial collaborators sought.

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.

