

## **Patient/carer involvement in clinical guidelines: the SIGN experience**

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The Scottish Intercollegiate Guidelines Network (SIGN) was established in 1993 and develops clinical guidelines for the NHS in Scotland using an internationally validated methodology. Guidelines are developed to promote effective health care by reinforcing good clinical practice and to promote change in professional practice where this does not comply with current best practice.

SIGN recognised the potential benefits of involving patients in guideline development and has been trying different ways of doing this since 1997. In 2000, the UK government released the paper *Our National Health: a plan for action, a plan for change* which recognised the value of engaging with members of the public to help make health services patient-centred. This led to the Scottish Executive Health Department funding a one year project in 2001 to further develop the way SIGN involved patients in guideline development. This dedicated funding allowed SIGN methodology for involving patients to develop significantly and become embedded so that patient involvement is now an integral part of the guideline development process.

By involving patients and carers in the guideline development process SIGN can be sure that the guideline addresses the key issues that matter to patients and carers and can make sure patients' and carers' perspectives, needs and preferences are reflected in the guideline.

SIGN adopts various methods to identify patient concerns depending on the guideline topic. These include:

- Carrying out a patient focused literature search
- Canvassing opinion through the SIGN patient network and patient organisations e.g. Meningitis Trust
- Including a minimum of two patient representatives on each guideline development group
- Using or holding focus group meetings
- Visiting patient groups to consult on draft documents
- Inviting patient groups to attend national open meetings to comment on the draft guidelines
- Inviting at least one lay reviewer to take part in the peer review process

A patient focused literature search strategy was developed by and is carried out by the SIGN Information Team. The aim of this literature search is to identify what the published literature says (both qualitative and quantitative) in terms of patients' and carers' issues of concern in relation to the clinical topic. Results

from the search are sorted into “key themes” which are reviewed by the guideline development group and incorporated into the key questions.

Patient representatives on groups have a number of roles including ensuring patient/carer perspectives are taken into account when the guideline development group drafts the recommendations, helping to draft the information for discussion with patients and carers section of the guideline and helping SIGN with consultation exercises. One of the most important roles for patient and carers representative is helping to “feed in” patient and carer issues to guide the key questions. To achieve this patient representatives need a committed chairman and Programme Manager who supports and involves them. In addition to support from the chairman and Programme Manager, SIGN offers formal training for patient representatives and constant support from a designated member of SIGN staff.

Many organisations who involve patients in their work often ask themselves “does patient involvement make a difference?” Experience at SIGN has shown that patient involvement can make a difference to guideline development. For example, SIGN 32: Coronary revascularisation in stable angina (1998) involved one patient representative who was recruited via the group chair due to the non-existence of a recruitment methodology. The patient representative was interested and contributed to the guideline however his involvement did not have a significant impact on the guideline. In contrast, Management of stable angina (2007) had patient representatives who had full training and support. The guideline contains a full chapter on patient issues, including evidence based recommendations and an additional chapter on psychological and social issues. Likewise, information collected from patient groups and from the SIGN patient literature search has for some guideline topics led to the formation of extra key questions or changes to existing key questions.

SIGN has begun to develop patient versions of the clinical guidelines. Patient versions allow patients and carers access to the recommendations in the guideline and help to make patients aware of what tests and treatments they can expect to receive from the NHS. The patient representatives helped to select the most important recommendations from the clinical guideline and advised on how information should be presented. Significant involvement of patient and carers is required at the consultation stage of the development process.

Patient involvement is a difficult task; SIGN is committed to evaluating and trying to improve how it is done. A self administered questionnaire is now issued to patient representatives at certain stages of the guideline development process to monitor their experience. As SIGN is part of the special health board NHS Quality Improvement Scotland, there is a requirement of SIGN by the Scottish Executive for SIGN to complete a performance assessment framework to determine how well we are involving patients in our work.

There are still significant gaps in SIGN's methodology for involving patients. For example, we have not yet managed to engage with hard to reach groups such as ethnic minorities, people from areas of high deprivation and people with communication difficulties. SIGN is committed to taking approaches to involve people from a diverse range of backgrounds and is keen to collaborate with voluntary organisations and community health initiatives to engage with hard to reach groups of people.

To maximise patient involvement at SIGN, there is a need for better quality qualitative research evidence and better reported qualitative research evidence. Future developments include on-line participation by patients, development of further training courses, the introduction of a patient handbook and an "introduction to SIGN" electronic tutorial.