Involving patients in effective health care: assessing the feasibility of the use of a patient information leaflet in routine clinical practice

The context

Communicating effectively with patients and involving them in decisions about their care is a major priority for the UK National Health Service (NHS). The NHS Plan has outlined the need for high quality information to increase patients’ involvement in decisions about their care, and to inform their expectations of the treatments and services the NHS can deliver.1

In England, one of the standards set in the National Service Framework for Coronary Heart Disease (CHD) is that primary care health professionals should identify all people with coronary heart disease and offer them comprehensive advice and appropriate treatment to reduce their risks.2 In order to increase involvement in decisions about their care, patients need access to high quality information which they feel is relevant to their needs. Most patient information, however, is of poor quality, does not reflect available research evidence or meet information needs as described by patients themselves.3

This small scale (£15,000) nine month project, commissioned by North Yorkshire Health Authority, had the following aims:

- to develop an evidence-based information leaflet for people with established CHD;
- to undertake a small-scale pilot of the feasibility of the use of the leaflet in routine clinical practice.

Development of the patient information leaflet

High quality systematic reviews and other relevant research evidence were used to produce a clear, patient-friendly summary of current knowledge around CHD. A focus group of CHD patients was convened and asked about the information they and their families felt they needed in order to understand and manage their illness. At the same time, the group were given a copy of the draft leaflet and asked whether it met their information needs and was clear and understandable.

The responses from the focus group were then used to revise the leaflet which was then sent for peer review by professional and consumer representatives. Further revisions were made to the leaflet, in light of peer review comments, and it was then submitted to the Plain English Campaign in order to obtain their “Crystal Mark” for clarity and understandability of the text.

Feedback from patients

Survey questionnaire

Of the 48 questionnaires sent out, 36 were returned; a response rate of 75%.

The majority (n=33) of respondents thought that the leaflet had contained useful information; 58% (n=21) stated that their partner/family had found the leaflet useful in helping them to understand their condition. 28% (n=10) of respondents reported that some of the information contained in the leaflet was new, 94% (n=34) felt the order in which the information was presented was helpful and logical. Only 16% (n=6) of respondents reported using the record tables at the back of the leaflet.

In terms of discussing the leaflet with either the doctor or nurse, 64% (n=23) reported that they had not discussed the leaflet. 72% (n=26) of respondents said they weren’t asked by the relevant health professional if they had any questions about the leaflet and 89% (n=33) said they themselves didn’t ask any questions.

All of the respondents had received information about their condition from other sources.

Focus group

Seven patients participated in a focus group convened to discuss the leaflet in more detail. The group made a number of specific points about the leaflet, the most important of which were:

- to undertake a small-scale pilot of the feasibility of the use of the leaflet in routine clinical practice.

Conclusions

This study demonstrates that it is possible to develop evidence-based patient information materials that takes account of patient preferences in a timely and efficient manner. The content and format of the leaflet appears to have been well received by patients and professionals alike. Although feasible to introduce, the pilot provided no evidence that the leaflets were useful in helping patients to initiate discussions with their health professionals. However, this pilot has identified some of the potential barriers to using the leaflet within the consultation and as an aid to greater participation in consultations. Such barriers will have to be overcome if the leaflet is to be made more widely available.

References