

# Involving patients in effective health care:

## assessing the feasibility of the use of a patient information leaflet in routine clinical practice

Paul Wilson,\* Amanda J Sowden,\*  
Ian Watt,\*\* Liz Newbronner,\*\*  
Chris Acton\*\*\*

\* NHS Centre for Reviews and  
Dissemination, University of York, UK.

\*\* Dept of Health Studies,  
University of York, UK.

\*\*\* Acton Shapiro Consultancy, Malton, UK.



### 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.<sup>1</sup>

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.<sup>2</sup> 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.<sup>3</sup>

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.

### A small-scale evaluation of the feasibility of using the leaflet in routine clinical practice.

General Practices within two North Yorkshire towns were contacted and asked to pilot the leaflet. Three practices plus the cardiac liaison nurse based at the local district general hospital agreed to take part.

Practice staff were asked to give the leaflet to all CHD patients attending for routine follow-up over a one month period. Before recruitment began, participating health professionals were briefed about how the leaflet should be used within the consultation.

One month after patients had agreed to take part in the study, they were sent a short postal questionnaire seeking their views on the format, content and presentation of the leaflet and the way in which they had received and used the leaflet.

Patients were also asked if they would be willing to participate in a focus group to discuss the leaflet in more detail and also talk about their views on the provision of patient information more generally.

48 patients were recruited within the pilot recruitment period.

### Feedback from patients

#### Survey questionnaire

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

The majority (n=32) 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 to them. This included information about the effects of drugs (n=7), cardiac rehabilitation (n=1) and the section on alcohol (n=1). One person stated that most of the information in the leaflet was new.

All of the respondents reported understanding either all (n=29) or most (n=7) of the language used in the leaflet. 94% (n=34) felt the order in which the information was presented was helpful and logical.

Only 18% (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=32) 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:

All participants had been given the leaflet with no real discussion of its purpose or contents. They felt strongly that the nurses should talk people through the leaflet, particularly with those who had recently had a heart attack or been diagnosed. They felt this would help people to understand the value of the information being given and allow people to ask questions.

Overall, the group felt the leaflet was very useful, especially for those who are newly diagnosed. They felt the language was clear and understandable, although the importance of using positive language was emphasised.

Generally, the focus group did not find the record card particularly helpful and would have preferred to see this space used to provide details of other sources of local and national help and information and for a glossary of terms.

### Feedback from participating staff

Semi-structured interviews with participating staff were conducted to explore any practical issues for professionals arising from the use of the leaflet, and to seek their views on the patients' responses to the leaflet.

In general all the nurses felt that patients responded positively to the leaflet although the cardiac nurse was fairly certain that very little of the detailed information would be taken in by patients at this stage of the recovery process.

The practice nurses reported difficulties in identifying patients as they tended to visit their surgery on an ad hoc basis and often consulted with GPs who the nurses thought did not give out leaflets.

The nurses involved sometimes actively chose not to give certain patients a copy of the leaflet. Either this was because the patient concerned was considered to be "unmotivated" or "unlikely to understand" the leaflet, or because the patient was elderly and much of the information concerned lifestyle issues which would not be applicable to this group.

The record card was not found to be useful by the practice nurses who preferred to keep all clinical information on their in-house record system. The cardiac nurse would have preferred a larger record card.

The practice nurses reported that they did not find the leaflet useful during consultations as they found it difficult to change consulting habits for just the pilot period. However, they felt that if the leaflets were to be made permanently available then they would become a useful consultation aid.

### 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.**

### Address for correspondence

Paul Wilson  
NHS Centre for Reviews and Dissemination  
University of York  
York  
UK  
YO10 5DD

Tel: +44 1904 434571  
Fax: +44 1904 433661  
Email: pmw7@york.ac.uk

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