

Time to mobilise expert patients' skills

It is one year since the Government's Expert Patient Programme pilots began. On 19 May, a seminar to discuss the expert patient concept was held at the Royal Pharmaceutical Society. Clare Bellingham finds out more about expert patients and how to mobilise their skills

PATIENTS with chronic diseases often seem to know more about their condition than the health professionals who are treating them. Each professional probably knows more about the technicalities of the disease within their specialist area. But, if nothing else, patients have the inside knowledge about what it is like to live with the disease, and the bigger picture of how each health professional contributes to their overall care. Often patients' knowledge is more extensive than this; for example, some undertake research into their condition.

The expert patient initiative is an attempt to harness this knowledge. Launched by the Government in September 2001, "The Expert Patient — a new approach to chronic disease management for the 21st century" describes how the National Health Service in England will help patients have more control over their care.

At the time of the launch, the chief medical officer Professor Liam Donaldson said: "Thirty years ago, the very idea of patients taking a lead in their own treatments and therapy would simply have been out of the question." How times have changed. Now it would be unthinkable for patients' views not to form part of the decision-making process. The expert patient initiative aims to move forward further still. Expert patients will be able to play a bigger part in managing their condition.

Of course, it is not for everyone. Some patients do not want to be an expert: they would rather a health professional took charge of their illness. In today's world of greater access to information, this group of people is decreasing in number.

WHY NOW?

Put simply, the expert patient initiative is happening now because the population is getting older. With older age comes chronic disease, so as more people live to older ages, the prevalence of chronic disease increases.

What does being an expert patient mean?

The expert patient initiative is about partnership. Patients with chronic diseases stop being passive recipients of health care. Instead, they are empowered to become partners in decisions about their care. Expert patients have a central role in their disease management, and they enjoy a good quality of life despite their condition.

This was not the case when the NHS was established 50 years ago. So the way that the NHS and the health professionals within it work needs to change in order to allow expert patients to reach their full potential.

In "The Expert Patient — a new approach to chronic disease management for the 21st century", eight recommendations are made:

- Creating an expectation that patient expertise is a central component in the delivery of care to people with chronic diseases
- Establishing a programme for developing more user-led self-management courses
- Identifying and addressing barriers to user-led self-management in the NHS
- Integrating user-led self-management into existing NHS care
- Ensuring that each primary care trust provides user-led self-management programmes for key chronic conditions
- Expanding the practical support available for user-led programmes provided by patients' organisations
- Promoting an understanding of the benefits of self-management programmes to health professionals through continuing professional development
- Establishing a national co-ordinating and training resources centre to help professionals keep up-to-date with developments in self-management

These changes will not happen overnight but, after an initial pilot stage until 2004, it is hoped that the concept will be in place across the entire NHS by 2007.

Speaking at a seminar at the Royal Pharmaceutical Society on 19 May, Annie Coppel, chairman of the faculty of prescribing and medicines management, College of Pharmacy Practice, commented: "Patients living with chronic disease can be more knowledgeable than health care providers. For too long, this knowledge has been an untapped resource." She added that these patients needed the confidence and skills to be able to play a central role in the management of their condition.

ROLE OF HEALTH PROFESSIONALS

How do pharmacists fit into the expert patient initiative? Well, chronic medication plays a central role in the management of many chronic diseases. So it would seem that pharmacist involvement is inevitable.

According to Ms Coppel, "there is a huge opportunity for pharmacists to pro-



vide high quality information and help patients to become experts. Pharmacists also have the opportunity to learn from patients in order to deliver better care in the future."

Speaking at the same seminar, Robert Hallworth, a pharmacist with diabetes, stressed the importance of communication. "Health care professionals don't talk to each other very much," he said. This means that information transfer between professionals is poor. A problem patients encounter is getting conflicting information from different professionals, he said. Perhaps with better communication, this type of problem could be solved.

For people with diabetes, the regular need for insulin prescriptions means that community pharmacists are the health professional they encounter most often. But Mr Hallworth wondered how much pharmacists intervened and how much they assisted in patient empowerment. "I've been to pharmacies with an insulin prescription and no one has asked me how I'm getting on with the insulin despite the fact that I am a new patient with a chronic condition at that particular pharmacy," he said.

Mr Hallworth told *The Journal* afterwards: "Pharmacists should think about providing services from a more patient-centred approach, and not what is easiest for staff," he said. He suggested that canvassing pharmacy users' views was a first step that pharmacists could take towards making the pharmacy more suitable and accessible for patients. "This might also provide more opportunities for pharmacist involvement," he added. For example, it might be more convenient for patients if some services provided locally were offered in a community pharmacy setting.

The second thing he suggested pharmacists could do is provide more information to patients — but only information that is pitched at the right level. Empowering patients is important, he said. After all, it is the patient who has to cope with a crisis at

3am when there are no health professionals around to help.

"Many people find that sharing information in groups works well. Pharmacists could find out what groups are being run locally and try to get involved in these," Mr Hallworth suggested. "Often pharmacists are not involved in such groups so information about drug treatment is given by other people such as nurses."

He added: "I think that in the vast majority of cases, the pharmacists' input would be welcomed by both patients and other health professionals."

If pharmacists felt that they could not attend group sessions then he suggested they should find out what information groups were providing so that any information given at the pharmacy matched up.

PILOT SITES IN THE UK

In May 2002, the first wave of the Government's Expert Patients Programme (EPP) pilot sites began. Initially, 25 primary care trusts were involved but the number has quickly grown. The latest figures show that over 200 PCTs have agreed to be part of the programme, a Department of Health spokesman told *The Journal* this week. More than 100 PCTs have already run at least one course as part of a pilot programme.

The aim of EPP is to train people with chronic conditions to be able to manage their conditions better on a daily basis. "A pilot consists of four courses, and each course has six sessions which patients are invited to take part in. We would expect each PCT to run four courses, which the DoH pays for, after which we hope the PCT will continue the programme itself," the DoH spokesman explained.

The pilots are being based on the "Chronic disease self-management system" developed at Stanford University in the United States. It involves one two-and-a-half-hour session every week for six weeks. Each workshop involves between eight and 16 participants.

People with chronic diseases are trained in self-management by two trained volunteer tutors. Topics covered include pain

Defining the term "expert patient"

Roy Jones, an independent consultant in self-management, describes expert patients as people who:

- Know the quality of their lives is primarily up to them
- Believe they can exert significant control over their own lives
- Are determined to live a healthy life despite their chronic condition
- Are realistic about the impact of their disease
- Have worked out what services exist and can be accessed

The Government vision

The vision set out in the "The Expert Patient — a new approach to chronic disease management for the 21st century" involves more patients with chronic diseases:

- Improving, remaining stable or deteriorating more slowly
- Being able to manage specific aspects of their condition (eg, pain relief)
- Being less incapacitated by the consequences of their illness (eg, fatigue)
- Being able to access health and social care services appropriately
- Being able to gain and retain employment
- Being well-informed about their condition and medication, feeling empowered in their relationship with health care professionals and having higher self esteem
- Contributing their insights for the improvement of services and acting as advocates for others

management, medication, diet, exercise, communication and "breaking the symptom cycle". Course participants are also given a manual called "Living a healthy life with chronic conditions" written by researchers at Stanford University and adapted for use in the United Kingdom.

The EPP will be formally evaluated by the National Primary Care Research and Development centres at the Universities of Manchester and York. A DoH spokesman said that the formal evaluation had only just begun so it was too early to say what the outcome would be. He added: "We have received anecdotal feedback from the EPP pilots and this has been encouraging."

Further information about progress in the pilots can be found at the DoH website at www.doh.gov.uk/cmo/progress/expertpatient. This website also contains a newsletter containing updates from the EPP. It includes testimonials from people involved in the EPP pilots.

Tom Stebbings, who has multiple sclerosis, was one of the first people to participate in an EPP course and is now a course tutor. He tells the newsletter: "Thanks to the course, I have managed to return to part-time work and stop some of my painkillers. There are hundreds of chronic conditions but the four things that emerge during the sessions time and time again are mobility, pain, depression and loss of self-esteem. We teach people how to manage them and how to concentrate on something else. You may have to downsize your aspirations but it isn't all doom and gloom."

And to provide a health professional's point of view, Dr Stuart Eastman, a general practitioner in Wiltshire, is quoted as saying: "Mrs N, who has osteoarthritis, has, since attending a self-management course, become less dependent on myself and her physiological well-being has greatly improved. The doctor-patient relationship has become one of mutual co-operation rather than one of dependency. I have seen this trend being repeated with patients who are on an EPP course at the moment."

INTERNATIONAL PERSPECTIVE

Although the term "expert patients" is used in the United Kingdom, the concept it describes is being developed in many other countries too. Outside the UK this concept is known as "self-management".

Dr Malcolm Battersby, director of the Finders University human behaviour and health research unit in Australia, told last week's meeting that there is an emerging international interest in self-management. He gave six principles of self management:

1. Know your condition
2. Have active involvement in decision making
3. Follow the care plan that is agreed with health professionals
4. Monitor symptoms associated with the condition and respond to them
5. Manage the physical, emotional and social impact of the conditions
6. Live a healthy lifestyle

A programme called "Partners in health" was designed on the basis of these principles. He emphasised that the programme was about partnership. "You should not empower the patient without empowering the clinician," he cautioned. So it involved education for clinicians as well as interventions for patients such as a monitoring diary and a symptom action plan.

Evaluation of the programme found that 70 per cent of patients felt better able to cope with life. Furthermore, 75 per cent of general practitioners felt that their patients were managing their health better and 50 per cent of GPs had substantially changed their own management of patients as a result of participating in the pilot.

MOBILISING EXPERT PATIENTS' SKILLS

Can expert patients be created? "I seriously doubt it," said Roy Jones, an independent consultant in self-management, at last week's seminar. "But there are many people who could pursue an active rather than inactive route and become self-managers." He believes that many more people will choose this pathway in the future.

The concept of expert patients needs to be promoted to both the general public and health care professionals because it is not yet widely accepted. Change will happen gradually and by 2007 it is a concept that will form part of pharmacists' daily practice. But that should not stop pharmacists getting involved now.

Pharmacists are well-placed to encourage expert patients. It is time to mobilise patients' knowledge and skills.