

## National Evaluation of the Expert Patients Programme

### Key findings (Research into Expert Patients - Outcomes in a Randomised Trial)

After 6 months there were:

- moderate gains in self-efficacy;
- small gains in energy;
- improvements in quality of life equivalent to one additional week in perfect health over a period of 12 months;
- small gains in secondary outcomes such as psychological wellbeing and partnerships with doctors;
- high satisfaction with the course;
- no impacts on routine health service use (e.g. GPs, practice nurses and outpatient visits);
- some reductions in costs of hospital use (inpatient and day case);
- increases in out of pocket costs (for e.g. payments for alternative therapies, domestic help and special dietary needs);
- no major increases in overall costs, because the costs of sending people on the course were recouped from savings elsewhere in the system.

The cost-effectiveness of EPP is due to there being little difference in costs between the trial groups and an improvement in health-related quality of life scores in the EPP group. Total costs in both groups were similar as the increased patient costs together with the cost of delivering the intervention was offset by reductions in resource use.

Lay-led self care skills training courses are moderately effective in improving self-efficacy and energy levels in people with long-term health conditions and are likely to be cost-effective. There is no significant impact on health utilisation at the level of community and primary care.

- Such courses are useful additions to the range of current services for the management of long-term conditions.
- The course is likely to be cost effective, given current conventions about the value of increased quality of life.

### Background

This summary presents findings relating to the implementation and effectiveness of the Expert Patients Programme (EPP) during its pilot phase. Implementing the EPP into the NHS has had two components: running the actual self care training courses for patients; and the action required to link this to other programmes and policies encouraging self care of long-term health conditions already provided by the NHS, other agencies and patients.

## Self-management support

The Expert Patients Programme (EPP) was launched by the Department of Health in England in 2001 with the aim of establishing lay-led self-management programmes in the NHS<sup>1</sup>. The mainstay of the EPP is a six-week self care skills training course which is an adaptation of the Chronic Disease Self-management Programme developed in the USA<sup>2</sup>. The course is delivered through PCTs by people who have personal experience of living with a long-term condition. The course is open to anyone with a long-term condition and is generic rather than condition specific. At NPCRDC we have completed a national evaluation of the EPP to explore how it was implemented and its clinical and cost-effectiveness.

## Methods

A range of methods was used for the national evaluation of the EPP:

1. A randomised controlled trial (RCT) to find out whether the course improved patients' outcomes and was cost-effective for the NHS;
2. A personal experience study to examine patients' experience of undertaking the EPP training and to compare the experience, ways of living with a long-term condition, personal self-management strategies and use of services prior to and after attending the training programme;
3. A process evaluation to study implementation by PCTs and to find out how differing local contexts influenced the running of the programme.

## Results

### Randomised Controlled Trial (RCT) REPORT (Research into Expert Patients Outcomes in a Randomised Trial)

The RCT involved 629 participants in England with self-defined long-term conditions, who were randomised to either the EPP course or to a waiting list for the course. Patient outcomes were measured at six months. Our model for how the EPP works was based on the hypothesis that changes in self-efficacy (belief in one's capability to produce an effect) would lead directly to changes in health status, which in turn would influence health care utilisation. At the point of recruitment participants did not have strong preferences for fast access to an EPP course. Altruism (the desire to help others with long-term conditions) was a key motivator for trial participation.

The EPP course increased patients' self-efficacy by a moderate amount, and had a relatively smaller impact on the amount of energy people reported (energy was chosen as the health status outcome most relevant to people with a range of long-term conditions).

The effects of the course on patients' use of health services was varied. Routine health service use (such as GPs, practice nurse and outpatient visits) was unaffected, but the course did reduce the costs associated with overnight hospital and day case use. Patient reported increased out-of-pocket expenses. Overall, the costs in both groups were similar, because the costs of sending people on the course were recouped from savings elsewhere in the system. There were small gains in secondary outcomes including psychological wellbeing and partnerships with doctors. There was high satisfaction with the course and particularly the experience of being in a group. Additional benefits may include reduction in social isolation.

The health economics analysis looked at change in QALYs (Quality-Adjusted Life-Years) and cost-effectiveness<sup>3</sup>. QALYs are based on quality of life as measured by the EuroQol instrument (EQ5D) and the adjusted analysis can be interpreted as leading to one extra week of 'perfect' health per year for those on the EPP course. The EPP reduces health care costs, though patient out-of-pocket costs were higher for the EPP group suggesting the potential for cost shifting from the NHS. The programme is associated with improvements in outcomes and health related quality of life at no increased cost, and is therefore likely to be cost-effective.

The trial results indicate that provision of a lay-led self care support programme to a varied group of patients with long-term conditions is likely to be a useful addition to current chronic disease management provision. The results need to be interpreted with some caution. The results are pertinent to people who volunteer to go on such a course and not those with long-term conditions more generally. Therefore care must be taken in applying the results to individual patients and particular patient groups.

## Patient's experience of EPP

The qualitative personal experience study allowed us to explore some of the processes underlying the trial outcomes. Improved self-efficacy may be related to people feeling better about their actions because they were able to compare themselves to others in the group and to identify with others who share their experiences of living with a long-term condition. The course reinforced the value and salience of people's pre-existing self care activities, rather than initiating alternative behavioural changes. This may be due in part to the course being delivered in a generic form which did not include condition specific advice, so people who already saw themselves as good self-managers felt they had nothing new to learn. It also suggests that people may be content with the self-management strategies they have already developed. We found that the inclusion of educational material about certain topics (e.g. living wills) has the potential to disrupt or reinforce some aspects of illness adaptation and existing views about chronic illness and its prognosis. Positioning educational material within self-management courses highlights the complexities and sensitivities of planning for future educational interventions of this type.

Possible reasons for the lack of change in use of primary care services and outpatient attendances are:

1. Individuals had already established routines of consulting;
2. Service use is influenced by the supply side: i.e. organisational imperatives to attend for tests, monitoring and repeat prescriptions;
3. The delivery of the course is divorced from the advice and actions provided by professionals working in the health service.

People who reported more complex or troubled relationships with service providers (often those with symptoms conventional medicine could not explain satisfactorily) may be more likely to alter use or views about services as a result of course attendance. Some individuals moved on to use sources of help and support other than the NHS and attending the course legitimised feelings that people had reached the limits of what traditional service contact could do to help.

Analysis of written comments people made about the course showed that:

- Social support from the group was highly valued;
- The facilitation skills of the tutors were vital to the success of the groups' experience;
- The mix of conditions on the course impacted on the experience for some who would prefer a condition specific group with which they would be able to identify more easily.

## Embedding the EPP in the NHS

The new programme was difficult to fit in with the way the NHS normally provides services (which are condition specific accessed through a health professional) and provided across primary and secondary care. Health professionals, who had little in-depth knowledge or awareness of the course were difficult to engage. Recruiting sufficient people onto courses with a view to making an impact at a public health level was problematic. From an administrative point of view, running courses was labour intensive and time-consuming for PCTs. The management of volunteers was, in the main, poor as PCT administrators had no prior experience of this type of role.

In the initial phase, the EPP courses tended to draw in people who were already committed to self-managing and who tended to be white, middle class and well educated. An advantage of this was that such people were a good potential source for course tutors which allowed for the expansion of the programme. However, if those who stand to benefit most from learning self-management skills (in particular people from ethnic minority groups and areas of high deprivation) are disinclined to participate, then one disadvantage is the potential to increase inequalities. The course is constructed to benefit those who want to increase their self-efficacy and take on responsibility for self-improvement.

*A new voluntary workforce.* The success and cost-effectiveness of the programme is dependent on a volunteer tutor workforce. Tutors are highly committed to the programme and invest a great deal in terms of their time and effort. The experience of the EPP participants is dependent on a well facilitated course. There is no specific training for tutors in group facilitation yet both tutors and course participants felt that such training would be beneficial. The structured nature of the course is both a benefit and a shortcoming. It allows for a quality controlled product which appeals to administrators and purchasers and it provides tutors with a safe and secure teaching method. However, it can be unrewarding for participants when sections of the course are read from a handbook and when the highly valued discussions and sharing of experiences are curtailed by tutors instructed to keep to timings.

*Course content.* The course does not currently acknowledge the broader social issues and needs relevant to living with a long-term condition. There is presently no course content about negotiating with welfare agencies and claiming benefits - a key problem for people who are unable to work or who need assistance to return to work. The EPP could also be an opportunity to provide links between the NHS, social services and the Department for Work and Pensions. The 'Living Wills' aspects of the course are also emotive and felt to be inappropriate by some.

## Conclusions

In its current form the EPP is helpful for some individuals and is valuable as one of a range of options. Rather than being concentrated on a single course, central resources for self care support might also be directed at a variety of systems and interventions which are able to meet the wide range of needs of patients with long-term conditions.

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## Reference List

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2. Lorig K, Sobel DS, Stewart AL, Brown BW, Bandura A, Ritter P et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization a randomized trial. *Medical Care* 1999; 37(1):5-14.
3. Kind P. The EuroQol instrument: an index of health-related quality of life. In: Spilker B, editor. *Quality of life and pharmacoeconomics in clinical trials*. 2nd ed. Philadelphia: Lippincott-Raven; 1996.

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Further details of this research are available at: [www.npcrdc.ac.uk/r5.25](http://www.npcrdc.ac.uk/r5.25) The following paper is also available: Kennedy A, Reeves D, Bower B, Lee V, Middleton E, Richardson G, Gardner C, Gately C, Rogers A. *The effectiveness and cost effectiveness of a national lay-led self care support programme for patients with long-term conditions: a pragmatic randomised controlled trial*. *Journal of Epidemiology and Community Health* 2007;61:254-261; <http://jech.bmj.com/cgi/content/abstract/61/3/254?eaf>

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