Background paper on the Expert Patients’ Programme for NICE Expert Testimony

NHS policy envisages care for long-term conditions based around three tiers: case management for patients with multiple, complex conditions; disease management for patients at some risk, through guideline-based programmes in primary care; and self care support for low risk patients (70-80% of those with long-term conditions). The Expert Patients Programme (EPP) was launched by the Department of Health in England in 2001 the main aim of which was to improve self care support in the NHS. Importing the CDMSP intervention from the United States and attempting to implement it in the NHS is likely to be shaped by the service context. The structure and organisation of health services, the nature of patient populations and patterns of service utilisation differ between the two countries and it cannot be assumed that the evidence of the clinical and cost benefits associated would generalise to the NHS in England.

The Expert Patient report had nine aims in relation to the EPP over a six-year period. These were to:

i. Promote awareness and create an expectation that patient expertise is a central component in the delivery of care to people with chronic illness.

ii. Establish a programme for developing more user-led self-management courses to allow people with chronic diseases to have access to opportunities to develop the confidence, knowledge and skills to manage their conditions better.

iii. Identify and address the barriers to establishing the EPP in the NHS.

iv. Integrate the EPP into existing NHS provision of health care.

v. Ensure that each Primary Care Trust area has arrangements for user-led self-management programmes.

vi. Expand the practical support for user-led programmes provided by patients’ organisations in partnership with health and social care professionals.

vii. Build, as part of continuing professional development programmes, a core course which would promote health professionals’ knowledge and understanding about the benefits – for them as well as for patients – of user-led self-management programmes.

viii. Establish a national resource for expert patients and other stakeholders.

ix. Work closely with the leading patient representative bodies and main health professional bodies to provide consistency with the NSFs (National Service Framework) for long-term health conditions(1).

The intervention and aims of the evaluation

The mainstay of the EPP is a six-week lay-led self care skills course which is an adaptation of the Chronic Disease Self-management Programme (CDSMP) developed and evaluated in the USA(2). In its pilot stage, the course has been organised and delivered through Primary Care Trusts (PCTs) by people who have personal experience of living with a long-term condition (the course tutors). The course is ‘generic’, that is, open to anyone with a self-defined long-term condition and involves six 2.5 hour group sessions held weekly. Attendance at four or more was required for a patient to be considered a completer. Groups comprised 8-12 participants taught by a pair of lay trainers or volunteer tutors who were trained and subject to quality assurance.
The training programme is designed to equip people with long-term conditions to:

- lead a healthy lifestyle
- communicate with others more easily
- take care of pain, tiredness and depression
- use problem solving and action planning skills
- work better with professionals.

This national evaluation of the EPP contains linked research studies was designed to:

1. Through the process evaluation examine the implementation of the EPP within the structures and locality contexts of the NHS in England (PREPP);
2. Evaluate whether the intervention is clinically and cost-effective in this new setting (the randomised controlled trial outcome evaluation – REPORT); and
3. Examine personal experience of being recruited to and undertaking the EPP intervention against the background of peoples’ pre-existing ways of managing and living with a long-term condition (qualitative evaluation).

Results

The Randomised Controlled Trial (RCT) REPORT (Research into Expert Patients Outcomes in a Randomised Trial)(3)

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(4). 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). There was no change in health services utilisation (sum of GP consultations, practice nurse appointments, A&E attendances and outpatient visits) although overnight hospital stays and use of day case facilities were reduced in the EPP group.

The EPP intervention evaluated in this trial is very likely to provide a cost effective alternative to usual care in people with long-term conditions. The health economics analysis looked at change in QALYs (Quality-Adjusted Life-Years) and cost-effectiveness. 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 analysis showed the programme is likely to be cost-effective because there was an overall reduction in service utilisation which offset the costs of the intervention. This analysis demonstrates that the EPP is likely to generate QALY benefits with little or no additional cost, and that the EPP intervention is likely to be cost effective when compared with treatment as
usual at threshold values of cost-effectiveness. While the QALYs gained are small in absolute terms, an additional 0.02 QALY is equivalent to an extra one week of perfect health per year. When the value of a QALY is £20,000 the EPP has a probability of 94% of being cost effective. The higher probability of EPP being cost-effective compared to control is due to there being little difference in costs and an improvement in QALY scores in the EPP group(5). 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.

**Limitations and current likely cost-effectiveness**

However, the analysis did not consider any comparators other than usual care and this is a major limitation. Given the nature of the intervention, a group based therapy, comparing the EPP intervention with another group therapy would have been preferable, and may have led to a different conclusion. Therefore, while the results of this study are largely in favour of implementation of EPP, further research is required to introduce other relevant comparators into the analysis. Current prices charged for the courses by the EPP Community Interest Company (http://www.expertpatients.co.uk/public/cms/uploads/PriceGuide2008.pdf) suggests that cost effectiveness depends crucially on the number of people that are able to be recruited to a particular course.1

An additional study was conducted in order to assess how much patients with long-term conditions value self-efficacy (i.e., confidence in their ability to manage their condition) compared with other health outcomes, including measures of quality of life, and process outcomes including access to General Practitioners(6). We undertook a Discrete Choice Experiment (DCE) set in UK community settings. Participants: 367 patients (mean age 57.5) living in the community with a wide range of self-defined long-term conditions. Main outcome measures: the relative value that individuals place on four specific outcomes, namely, self-efficacy, Health Related Quality of Life (HRQoL), access to General Practitioners, and level of isolation. All models showed that participants were willing to trade substantial reductions in their HRQoL for improvements in their self-efficacy. This is potentially important where decisions are made on the basis of cost-effectiveness using Quality Adjusted Life Years as the metric. Exclusion of these outcomes may lead to the cost-effectiveness of these interventions being understated.

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.

In terms of those who are likely to benefit most participants with lower self-efficacy and health-related quality of life at baseline demonstrated more positive health outcomes. The Expert Patients Programme may have a

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1 Base case in our analysis was £250 per person. The current price of approx £5,000 per course, works out at £312.5 per participant. Assuming 16 participants, this which would lead roughly to an incremental cost of around £40 per participant (as EPP reduces their “other” costs by about £280 from our study). If we use our trial results of gain of 0.02 QALY per person, the ICER is about 2K per QALY which would still be considered good value for money. The crucial variable here is the number of participants; if only 6 attend, the incremental cost per person is around £570 (allowing for reduced resource use associated with EPP as above), and the ICER is 28K per QALY, which is more equivocal.
protective effect on health-related quality of life for patients with poor health and low confidence. Younger people benefited substantially more than older people(7).

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.

Explaining the outcomes

The qualitative personal experience study suggested that improved self-efficacy was related to people feeling better about their actions because they were able to make social comparisons with others in the group and 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 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. 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(8).

People who reported more complex or troubled relationships with service providers (often those with symptoms conventional medicine could not explain) 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(9).

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 a
Expert paper 1 – Expert patients’ programme (plus additional paper to support this expert paper). These papers were produced by Ann Rogers.

Challenge. 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(10) PCTs currently commission or run and administer courses. factors indicating future EPP success include collaborating across PCTs to share co-ordinators, tutors, and funding(11).

Lack of reach
In the initial phase, the EPP courses tended to draw in people who were already committed to self-managing with a disproportionate number of white, middle class and well educated recruits. 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. Difficulties with engaging people from ethnic minorities have also been identified by other research(12). The course is constructed to benefit those who want to increase their self-efficacy and take on responsibility for self-improvement which may exclude people who hold different personal goals and values(13).

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. . There are tensions inherent in this new role, which emerge from the consequences of having a long-term condition, their relationship to other occupations operating within primary care and their structural position within the NHS. Some see the volunteer tutor position as a stepping stone to future paid work and roles(14). Attitudes relating to personal goals, and better health were significant predictors of satisfaction with the tutor role. Only a small proportion of the variance in productivity was accounted for, and tutors were more likely to be productive when they were single, home-owners, car-owners, and had lower scores on the depression scale. Overall satisfaction and personal goals were predictors of retention(15).

Course content
The course does not currently acknowledge broader socio-economic issues relevant to living with a long-term condition and this is a key need amongst some participants(16). 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(17).

Conclusions
In its current form the EPP is helpful for some individuals and is valuable as one of a range of options. However, it has not been evaluated against other models of professionally or lay delivered self care support (18).
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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.

**Policy Relevance**

- 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 implementation of the course outside the main provision of NHS chronic disease management may limit future uptake impact and the engagement of professionals.

**Work and EPP**

There are some outcomes in the EPP programme related to work. These relate to the peoples’ work situation and change since attending the EPP compared with a control group. Hours of work, days off work, loss of earnings and loss/gain of leisure time. I will be able to present more data on this on the 11th September.

Being a volunteer tutors is a role which some people saw as gaining valuable experience - as the first step in obtaining paid employment and the course provides self –esteem and access to training and networks that may increase the likelihood of people seeing themselves as potential workers of the future.

The current lack of reach to disadvantaged groups in the population and relative divorce from other service provision may limit it’s capacity to engage those in primary care and with initiatives such as pathways to work. Other models of self care that are embedded in service provision may be more appropriate in this regard(19).

Reliance on peer/lay leaders means quick turnover and variable length of time

Volunteer role subject to maintenance of good will altruism and not the rewards of paid employment. Expenses received for carrying out this role sometime altered peoples’ eligibility to benefits.

Work place initiatives may enhance the link between self care management and pathways to work
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