The United Kingdom Expert Patients Programme: results and implications from a national evaluation

Anne Rogers, Anne Kennedy, Peter Bower, Caroline Gardner, Claire Gately, Victoria Lee, David Reeves and Gerry Richardson

ABSTRACT

- The Expert Patients Programme (EPP) is a central element of chronic disease management policy in the United Kingdom.
- It aims to deliver self-care support by developing peoples' self-care skills, confidence and motivation to take more effective control over their long-term conditions.
- A large, national randomised controlled trial found that the EPP's lay-led skills training was effective in improving self-efficacy and energy levels among patients with long-term conditions, and was likely to be cost-effective.
- Key questions remain as to whether existing outcome measures capture the core outcomes that are important to patients with long-term conditions.
- The development and evaluation of self-care support initiatives should take into account the extent to which self-care support initiatives can be integrated into peoples' everyday lives, and the degree of fit with patients' existing adaptations and strategies.
- Rather than being concentrated on a single course, central resources for self-management support should be directed at a variety of systems and interventions that are able to meet the wide range of needs of patients with chronic conditions.

MJA 2008; 189: S21–S24

The United Kingdom Department of Health envisages service delivery for long-term conditions designed around three tiers:

- *case management* for patients with complex conditions;
- *disease management* through primary care for patients at some risk; and
- *self-management support* for patients with low-risk long-term conditions.

The Expert Patients Programme (EPP) is a central element of chronic disease management policy in the UK. The program aims to deliver self-management support and improve the quality of life of people with long-term conditions by developing generic self-management skills and improving people's confidence and motivation to take more effective control over their lives and illnesses.

The mainstay of the EPP is a 6-week course based on the Chronic Disease Self-Management Program, which was developed and licensed by Stanford University.[1] Historically, volunteer organisations in the UK pioneered the use of peer-led training. In contrast, the EPP course was designed to be delivered within the National Health Service (NHS) by trained lay volunteers or paid trainers through health care organisations. During the pilot stage of the EPP, the course operated on an open-referral basis, and was available to anyone with a long-term condition. Box 1 gives details of the course content and delivery during the pilot phase (2002–2006).

Initially, the EPP was administered by Primary Care Trusts (PCTs; primary care organisations responsible for commissioning, organising and delivering community care). It is now operated by a community interest company set up by the UK Government to market and deliver courses and diversify the program. By the end of the pilot phase, the EPP had the capacity to train about 12 000 participants per year.

Evaluating the Expert Patients Programme

We conducted a national evaluation of the EPP, focused on the extent to which health service organisations could implement and mainstream such a program, and the clinical and cost-effectiveness of the EPP. A range of methods was used for the national evaluation:

- A process evaluation to study implementation by PCTs and to find out how the program was implemented in different contexts.
- A randomised controlled trial to determine whether the course was effective in improving patients' outcomes and was cost-effective for the NHS.
- A personal experience study involving individuals who had taken part in the randomised controlled trial, to examine patients' experience of the course and how it fitted with their existing efforts to self-manage.

Implementation

In terms of implementation, the power of the NHS to roll out a new program is illuminated by the uptake of the EPP nationally. At the end of the pilot phase of the EPP, results of a national survey of PCT leads suggested widespread participation and uptake by the primary care organisations charged with running local courses. About 10% of the 300 PCTs in the UK became enthusiastic champions of the EPP. The best predictor of success was time dedicated to the EPP, irrespective of organisation size. The PCT leads who dedicated the most time to the EPP (generally over 2 days a week) ran more courses, cancelled fewer courses, were able to attract and train more tutors to deliver courses, and were more likely to have significant plans for future courses.[2]

Effectiveness and cost-effectiveness

We recruited 629 patients with a range of self-defined long-term conditions to a randomised controlled trial. Outcomes were assessed in all patients regardless of the number of sessions attended (intention-to-treat analysis). Our comparator group was a 6-month waiting-list control group (a non-waiting-list comparator was excluded on the grounds of the ethical issues arising from denying access to treatment). Three primary outcome measures of effectiveness were examined 6 months after recruitment:

- *Self-efficacy* — a measure of belief in one's ability to achieve a goal; in this case, successfully managing life with a long-term condition.
- *Energy* — chosen as a health status outcome relevant to people with a range of long-term conditions.

1 Features of the Expert Patients Programme (EPP)

The EPP self-management skills training course

- Self-management of long-term conditions
- Developed in the United States and anglicised
- Lay-led highly structured 6-week generic course; each weekly session lasts 2.5 hours
- Topics include: pain and medication management, relaxation, diet, exercise, communication with health professionals, problem solving and action planning
- Not a medical model

Pilot program to embed EPP in the NHS between 2002 and 2006

- Four courses per PCT funded by government until 2004
- Set within NHS to avoid marginalisation
- Support personnel
  - ➢ Salaried trainers
  - ➢ Designated PCT leads
  - ➢ Volunteer tutors

NHS = National Health Service. PCT = Primary Care Trust. ◆

- *Routine health services utilisation* — the total number of general practitioner, practice nurse, emergency department and outpatient attendances by each patient in the trial over 6 months.

Additionally, cost-effectiveness outcomes were based on a comprehensive assessment of the costs of the program (primary care, specialist, community, medication and out-of-pocket costs) combined with a measure of health-related quality of life (EQ-5D,[3] which measures self-reported mobility, pain, anxiety/depression, self-management, and ability to perform usual activities).[4] The patterns of scores, weighted by UK population, allow estimates of quality-adjusted life-year (QALY) gains, and the economic analysis combines with these estimates to examine cost per unit gain in QALYs.

The main results are summarised in Box 2 and full results have been published previously.[5] The "effect size" is a measure of the overall impact of the program and can be used to compare the impact of the EPP with other interventions. Based on the effect size, referral to the program had a moderate positive impact on self-efficacy, a smaller impact on reported energy, and little impact on routine health services utilisation (Box 2).[5] Patients showed improvement in health-related quality of life equivalent to providing them with an extra week of perfect health per year, and combining costs and outcomes showed the program was likely to be cost-effective.[5] This reflected the fact that the program improved health-related quality of life but did not add to the total costs of care, because reductions in service use (especially expensive inpatient stays) offset the costs of providing the self-management skills course (Box 3). One issue to note is that patients' out-of-pocket expenses increased.

Personal experience

The nested qualitative study undertaken alongside the trial identified additional possible benefits for patients. These included a valuing of social support from participating in a group, and reduction in social isolation. Increased social networks made possible through contact with new people was one unexpected feature reported by a number of participants.[6]

2 Primary outcomes from the randomised controlled trial[5]

Outcome	Adjusted difference (95% CI)	*P*	ES
Self-efficacy	8.0 (6.2 to 11.5)	< 0.001	0.44
Energy	3.7 (1.2 to 6.3)	< 0.001	0.18
Routine health services utilisation	–0.2 (–1.4 to 1.0)	0.73	0.03

ES = effect size. Conventionally, an ES of 0.8 is large, 0.5 is medium and 0.2 is small. ◆

The role of the Expert Patients Programme in context

The results of the trial suggested that the model of training used is likely to make a positive contribution to the management of long-term conditions. Additionally, the EPP has set a clear new agenda for such management. It has centred on developing an approach which is user-focused, based on individuals who are active and able to solve problems themselves and challenge an over-medicalised approach to the management of long-term conditions. Nonetheless, some key questions remain, including:

- Can the program engage with all patients with long-term conditions?
- How important is self-efficacy to patients?
- How can the program be integrated with existing ways that patients manage their long-term conditions?
- What is the role of other models and approaches?

Can the program engage with all patients with long-term conditions?

As the EPP was conceptualised as a public health intervention, reach and engagement become key factors in equitably connecting with those most likely to benefit. Our process evaluation revealed that the EPP appealed most to white middle-class people with long-term conditions who already viewed themselves as effective self-managers.[7] A key limitation was that, relative to the numbers of people in the population with a chronic illness condition who were likely to benefit, there was poor uptake and attendance. Another study examining a lay-led self-management initiative, of ethnic minority groups living in a deprived inner-city area, found similar results.[8]

How important is self-efficacy to patients?

Traditionally, self-efficacy has been thought to mediate the effects of lay-led self-management courses. That is, the course increases patients' confidence in their ability to manage their problems, which in turn improves other outcomes. Although research using discrete choice methods has shown that self-efficacy is something that is clearly valued among the participants of the EPP trial,[9] the importance of self-efficacy as an outcome rather than process measure may have been overstated.

Using mixed qualitative methods, we found that some expectations were not dealt with because the self-management skills training program prioritised improvements in self-efficacy and did not engage with patients' material and social needs. An approach that focuses on self-efficacy may inadvertently sideline the relevance of social inequalities in patients with long-term conditions, and patients' personal experience and their adaptation to their long-term conditions.

3 Mean resource use and total costs of the Expert Patients Programme (EPP) compared with a waiting-list control; 629 patients were recruited between April 2003 and March 2005

	EPP group		Control group		
	Mean	*n*	Mean	*n*	Mean difference (95% CI)
Inpatient length of stay (days)	0.80	246	1.59	272	–0.79 (–1.75 to 0.18)
Medication costs	£426	243	£450	267	–£23.57 (–£174 to £127)
No. outpatient appointments	2.73	248	2.91	273	–0.18 (–1.17 to 0.81)
No. general practitioner appointments (at GP surgery)	3.36	246	3.44	269	–0.08 (–0.65 to 0.49)
No. general practitioner visits (at patient's home)	0.09	247	0.18	268	–0.09 (–0.18 to –0.01)
No. practice nurse appointments (at GP surgery)	1.37	247	1.59	271	–0.22 (–0.77 to 0.32)
No. district nurse visits (at patient's home)	0.31	237	0.23	264	0.08 (–0.34 to 0.52)
No. counsellor appointments	0.64	237	0.60	263	0.04 (–0.46 to 0.54)
Total cost, including patient costs*	£1912	313	£1939	316	–£27 (–£422 to £368)

* Of the EPP intervention (costed at £250 per patient).

For instance, social comparison is a process that is important in enhancing self-efficacy in group-based programs, but this can have a negative effect. Being poor and ill brings with it the possibility of shame and insecurity,[10] which may be reinforced in group situations. Attention to people's self-defined needs and access to comprehensive welfare support payments might be as or more important in improving self-management than programs based on psychological outcomes such as self-efficacy.

How can the program be integrated with existing ways that patients manage their long-term conditions?

The relevance of patients' existing work and adaptation deserves more prominence in the design of self-management programs. We know from the comprehensive research within the sociology of health and illness that being diagnosed with a long-term condition has important facets, including a search for meaning and legitimacy, a renegotiation of self in everyday life and a need for access to material and social resources. It is also clear that patients who participate in self-management interventions bring with them existing ways of managing.[11] The extent to which programs like the EPP fit with existing ways of managing are important in determining whether patients will accept them.[11]

Reflection on a failure to engage on these terms requires consideration when devising self-management interventions. This includes an assessment of the meaning of the disease to the person, the timing and the stage in a person's illness career and the fit with people's prior beliefs and lifestyles.[12] Arguably, the focus on the introspection of the individual "activated" or "expert" patient threatens to exclude from consideration the role played by significant others, family members, social networks and resources, including those to be found on the Internet, in facilitating support.[13]

What is the role of other models and approaches?

A final consideration is the extent to which different approaches to self-management support need to be considered in the light of limitations to the current patient-focused approaches to self-management support. We suggest a different focus may be required. Patients with long-term conditions already have relationships with clinicians and services. We have suggested elsewhere the need for self-management interventions to focus on three levels: the patient, the organisation, and the health professional.[14] Augmenting and modifying what patients already do to manage their health and illness may have little impact if clinicians are not ready to engage patients in a shared approach to care, supported by the wider context of the health service in which they work, and without considering the access patients already have to social and material resources in their everyday lives.

Conclusion

Lay-led self-management skills training courses used as the basis of the EPP were moderately effective in improving self-efficacy and energy levels in people with long-term health conditions and are likely to be cost-effective. Such courses are useful additions to the range of current services for the management of long-term conditions, and implementation via primary care organisations was shown to be feasible. In its current form, the EPP is helpful for some individuals and is valuable as one of a range of options. However, other options, which take account of existing patient management strategies and their contact with services, together with recognition of social and material resources, may be preferable in the longer term. Rather than being concentrated on a single course, central resources for self-management support should also be directed at a variety of systems and interventions that are able to meet the wide range of needs of patients with long-term conditions.

Competing interests

None identified.

Author details

Anne Rogers, PhD, Professor of the Sociology of Health Care[1]
Anne Kennedy, BSc, SRN, PhD, Research Fellow[1]
Peter Bower, PhD, Reader in Health Services Research[1]
Caroline Gardner, BSc, Research Interviewer[1]
Claire Gately, BSc, MSc, Research Associate[1]
Victoria Lee, PhD, Research Associate[1]
David Reeves, BSc, PhD, Senior Research Fellow[1]
Gerry Richardson, MSc, PhD, Senior Research Fellow[2]

1 National Primary Care Research and Development Centre, University of Manchester, Manchester, UK.
2 Centre for Health Economics, University of York, York, UK.
Correspondence: anne.rogers@manchester.ac.uk

References

1 Lorig KR, Ritter P, Stewart AL, et al. Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Med Care* 2001; 39: 1217-1223.
2 Lee V, Kennedy A, Rogers A. Implementing and managing self-management skills training within primary care organisations: a national survey of the expert patients programme within its pilot phase. *Implement Sci* 2006; 1: 6.
3 Tamim H, McCusker J, Dendukuri N. Proxy reporting of quality of life using the EQ-5D. *Med Care* 2002; 40: 1186-1195.
4 Richardson G, Kennedy A, Reeves D, et al. Cost effectiveness of the Expert Patients Programme (EPP) for patients with chronic conditions. *J Epidemiol Community Health* 2008; 62: 361-367.
5 Kennedy A, Reeves D, Bower P, et al. 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. *J Epidemiol Community Health* 2007; 61: 254-261.
6 National Primary Care Research and Development Centre. The national evaluation of the pilot phase of the Expert Patients Programme — final report. Manchester: NPCRDC, 2006. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080680 (accessed Oct 2008).
7 Kennedy A, Rogers A, Gately C. Assessing the introduction of the Expert Patients Programme into the NHS: a realistic evaluation of recruitment to a national lay-led self-care initiative. *Prim Health Care Res Dev* 2005; 6: 137-148.
8 Griffiths C, Mitlib J, Azad A, et al. Randomised controlled trial of a lay-led self-management programme for Bangladeshi patients with chronic disease. *Br J Gen Pract* 2005; 55: 831-837.
9 Richardson G, Bojke C, Kennedy A, et al. What outcomes are important to patients with long term conditions? A discrete choice experiment. *Value Health* 2008; 18 Jul [epub ahead of print].
10 Kennedy A, Rogers A, Crossley M. Participation, roles, and the dynamics of change in a group-delivered self-management course for people living with HIV. *Qual Health Res* 2007; 17: 744-758.
11 Gately C, Rogers A, Sanders C. Re-thinking the relationship between long-term condition self-management education and the utilisation of health services. *Soc Sci Med* 2007; 65: 934-945.
12 Chapple A, Rogers A. "Self-care" and its relevance to developing demand management strategies: a review of qualitative research. *Health Soc Care Community* 1999; 7: 445-454.
13 Sanders C, Rogers A. Theorising inequalities in the experience and management of chronic illness: bringing social networks and social capital back in (critically). *Res Sociol Health Care* 2007; 25: 15-42.
14 Kennedy A, Rogers A, Bower P. Support for self care for patients with chronic disease. *BMJ* 2007; 335: 968-970.

(Received 10 Jul 2008, accepted 28 Sep 2008) ❑