Assessing the introduction of the expert patients programme into the NHS: a realistic evaluation of recruitment to a national lay-led self-care initiative

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The study objective was to explore the way in which the expert patients programme (EPP) has been implemented by primary care trusts (PCTs) and to identify key barriers and facilitators to the implementation of this initiative in the National Health Service (NHS). The study forms the first part of a process evaluation to record the development of the EPP in the NHS and to identify the patterns of development which impact on NHS organizations and local community partnerships and networks. This preliminary survey consisted of telephone interviews with the key personnel working in primary care sites where EPP was initially piloted. Forty-six PCT leads (74% of those eligible) and 19 EPP trainers were interviewed (68% of those eligible). Secondary sources of data (such as PCT websites and literature promoting the EPP courses) were also examined. The PCTs' ability to recruit to EPP courses was considered a key marker of early success which in turn related to wider issues concerning EPP's position in the PCT's priorities and the degree to which it was *seen* or *made* to link with other agendas and goals. A quarter of the sample had good rates of recruitment, the characteristics associated with these sites included: location in urban areas; early access to voluntary tutors; delegation of administrative responsibilities; networking and sharing resources with other PCTs; use of local newspapers to publicize courses; and active support from health professionals. Problems with recruitment were associated with a reliance on a paper-based strategy; poorly developed links to the broader community and health professionals. The evaluation shows that initial success of a lay-led self-care support programme in the NHS depends on commitment at the level of the PCT boards as well as those directly charged with organizing and delivering pilot training courses. Helping key health professionals understand and engage with the principles and benefits of training in self-care for people with long-term health conditions is likely to impact on the success and future of this programme within the NHS.

Key words: chronic disease; long-term health conditions; primary care; process evaluation; public health; self-care; self-management

Introduction

The White Paper *Saving lives: Our Healthier Nation* (Department of Health, 1999a) draws attention to the contemporary burden of long-term health conditions, an increasing challenge in the UK and elsewhere. The promotion of best practice in ameliorating symptoms and secondary and tertiary prevention strategies are one means being used to tackle the impact of long-term health conditions.

In the UK, the National Service Frameworks (NSFs) mark a new phase in the management of long-term health conditions (such as coronary heart disease and diabetes) by providing an

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evidence-based template to set new quality standards for the delivery and monitoring of health services (Department of Health, 2002a). Alongside the introduction of these NSFs, self-care interventions for long-term health conditions have increasingly been recognized as an effective 'public health' strategy for improving quality of life and health outcomes for individuals suffering from a range of long-term health conditions. Dedicated self-care education training has been found to improve peoples' confidence and ability to take care of themselves and engage in collaborative shared decision making with health professionals (Von Korff *et al.*, 1997; Robinson *et al.*, 2001; Bower, 2002; Kennedy *et al.*, 2003). Randomized controlled trials provide the most rigorous evidence for effectiveness. The chronic disease self-management programme (CDSMP) is one example of a programme for which there is evidence of effectiveness (Lorig *et al.*, 1999). The Department of Health initiated the development of an anglicized version of the Stanford model, the expert patients programme (EPP), to help people with long-term health conditions and set up a task force with the requirement that it: 'set out the relationship between such programmes and the support which people require from the National Health Service (NHS). It will design a pilot programme and provide advice on what needs to be done to make services for people with long-term health conditions a central part of the NHS' (Department of Health, 2000: paragraph 3.50). Other work is also being undertaken in the Department of Health to support self-care (Dost, 1999).

A UK-based trial is needed because importing an intervention from the USA and attempting to implement it in the NHS is likely to be shaped by the service context. The structure and organization of health services, the nature of patient populations (Barlow *et al.*, 2001) and patterns of service utilization differ between the two countries and it cannot be assumed that the evidence of the clinical and cost benefits associated with the CDSMP in the USA will generalize to the NHS in England. The preliminary survey reported here forms part of a larger programme of evaluation:

1) A randomized controlled trial designed to evaluate clinical and cost-effectiveness.
2) A process evaluation designed to record the natural history of the project and identify the patterns of development which impact on NHS

organizations and local community partnerships and networks. The preliminary survey forms part of this evaluation and examines how the EPP was being bedded down and implemented in the first and second wave pilot sites.

However, there is more to these programmes than an individualistic approach, there is also a public health and community development perspective. Self-care approaches that extend beyond an individual focus to include wider community and organized health care systems (Wagner *et al.*, 1996; Kennedy and Rogers, 2001) have been advocated and introduced by Kaiser Permanente, an American Health Management Organization who have implemented the CDSMP (Lorig *et al.*, 2001). Other health organizations have introduced various forms of chronic care models which have self-care components (Bodenheimar *et al.*, 2002). In Australia, the Sharing Health Care initiative is a national programme designed to address the challenges of long-term health conditions through self-care strategies (Feyer *et al.*, 2003). In line with these international exemplars the implementation of the EPP incorporates a distinctly public health dimension by recognizing the need for the integration of self-care support into the NHS via the new primary care organizations (Von Korff *et al.*, 2002). The EPP, which aims to introduce a self-care programme embedded and integrated into the NHS, represents an initiative which requires implementation at the level of organizations and community. This latter emphasis on widespread dissemination aims to tackle the burden of long-term conditions as an intricate part of public health policy. As such the EPP can be viewed as one of a number of complex contemporary public health initiatives designed to reduce inequalities and to reach out to and provide coverage at the population level (e.g., HAZ policies, inequalities, urban regeneration, social inclusion). Efforts will be made at the national level to make the EPP available in the NHS equally to people from different age, gender, ethnic, geographical and hard to reach groups.

Connell *et al.* (1995) have described the three defining characteristics of comprehensive community initiatives (CCIs) as: aiming to 1) promote positive change in individual, family and community circumstances; 2) improve the social economic conditions and service resources in disadvantaged communities and 3) place a strong emphasis on community and neighbourhood empowerment. The

incorporation of self-care programmes for people with long-term health conditions into systems of health care delivery, nationally and internationally indicates the need for a greater focus on evaluating the way in which implementation of such programmes is taking place, which takes account of the responsiveness and role played by the relevant organizations and agents. Self-care evaluation designs to date have tended to focus on outcomes at an individual level although national evaluations elsewhere are beginning to be concerned with a range of factors that extend beyond the individual client level (Feyer *et al.*, 2003).

The purpose to this article is to explore the way in which the EPP has been implemented during its pilot phase in the context of primary care trusts (PCTs), and to identify and discuss barriers and facilitators in relation to the implementation of this initiative.

Embedding the EPP into the NHS

The process of embedding the EPP into the NHS has 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 and other agencies.

The EPP is based on the Stanford CDSMP model (Lorig *et al.*, 1999). The course consists of six 2.5-hour sessions, run by lay trainers (employed and appointed by the NHS) and tutors (lay volunteers). The aim is to enable participants to more effectively take care of their long-term health condition, through the development of problem-solving skills and the opportunity afforded by the group to exchange ideas and suggestions. Topics covered during the course include: relaxation, diet, exercise, fatigue, breaking the symptom cycle, managing pain and medication, and communication with health and social care professionals.

In England, PCTs are the organizations responsible for the implementation and promotion of these types of population and community measures in the improvement in health care (Department of Health, 2002b). PCTs have full control of budgets to provide and commission a wide range of community services on behalf of their patients (Wilkin *et al.*, 2001).

The process evaluation

Process evaluation provides a means of adding depth and perspective to the understanding of and implementation of policy. Compared to individual impact outcomes (e.g., in the case of self-care support initiatives, self-efficacy or improvements in health) process measures indicate what worked well and what did not, in what context at the level of organizations and within communities (Pawson and Tilley, 1997). Process information enables the identification of whether something fails or succeeds because of the way in which it is being implemented in practice and whether or not it was a success in a way which was not anticipated. There are a range and different levels of processes which can be evaluated. Pickin *et al.* (2002), in the context of the capacity of statutory organizations to engage with lay communities, point to the relevance of a community's capacity to engage with a particular policy; the skills and competencies of organizational staff; the professional service culture operating in a locality, the overall organizational ethos and culture, and the dynamics of the local and national political systems. Of most relevance to the process evaluation of self-care support are the three inter-related process evaluation aims identified by Nutbeam (1998) in relation to the implementation of health promotion initiatives. These are:

- *Programme reach*: did the programme reach all of the target population.
- *Programme acceptability*: is the programme acceptable to the target population.
- *Programme integrity*: was the programme implemented as planned, i.e., the extent to which the programme is able to reach target populations.

Methods

Telephone interviews were undertaken between March and May 2003. There were 62 PCTs in the first and second wave EPP pilot sites and 46 EPP leads were interviewed. Trainers are based in zones which are co-terminus with the 28 newly formed strategic health authorities, 19 trainers were interviewed. The semi-structured interviews were based on a checklist of topics which were initially generated by the research team (see Box 1). Interviews

were recorded and transcribed. PCT leads were also asked to complete a questionnaire about each course they had run. Additional documentary analysis was done on the content of PCT websites (where they existed) searching for mention of the EPP and on the leaflets and promotional material produced by the PCTs.

The data was analysed in terms of a realistic evaluation as proposed by Pawson and Tilley (1997) whereby the policy context is considered and assumptions about mechanisms and expected outcomes are first clarified and then reconsidered and evaluated in a realistic way in the light of what has been observed as happening in the real world allowing an explanation of why the implementation of the EPP worked or failed at an organizational level. Agreement around meaning was established through regular discussions and comment throughout the interviewing, collection, collation and analysis of interviews (A.K., A.R., C.G.), similar themes across interviews were identified and those relating to recruitment are

Box 1   Checklist of topics

Question	Prompts
1) What do you consider your current responsibilities are regarding the EPP?	Point of contact Advertising Administration
2) Please talk through the current mechanisms involved for a participant who wants to get on a course.	First point of contact Waiting time
3) How do you decide what types of participant should be in a particular group?	Disease specific Geographical location Language, ethnic and cultural issues Gender issues Mental health issues
4) How are courses being advertised and how are you making people aware of the EPP?	What approaches have been successful Which have been unsuccessful Use of local media Use of local interest groups
5) What has support been like locally?	GPs Hospitals Voluntary and community groups Other statutory agencies such as Local Authorities and others Other initiatives such as HAZs, New Deal and others
6) What sort of problems have you come across in getting courses off the ground?	Participant numbers Venues
7) What sort of future do you see for the EPP in your area?	Changes to current set up Views on sustaining EPP How has EPP helped in meeting goals and targets such as NSFs, activity levels, waiting lists?

reported here. A report giving a more detailed analysis is available (Kennedy *et al.*, 2004).

This initial survey was designed to illuminate how this national blueprint for self-care has initially been implemented at local PCTs by key stakeholders. Recruitment is concerned with marketing, reach and recruitment of voluntary tutors (lay volunteers trained to deliver courses by EPP trainers) to perpetuate the programme. In the early phase of the process evaluation an initial question was the capacity of PCTs to promote recruitment. The ability to recruit to courses was considered a key marker of early success because the ability to engage with individuals (particularly those from marginalized groups) is a necessary condition for those people to benefit from self-care.

Analysis of the data

The policy context and its relationship to the expected outcomes of the EPP is summarized in Table 1.

The role of PCT leads, trainers and tutors in the recruitment to the EPP

During the pilot phase of the EPP, PCTs received central funding to run four courses in their local area. An individual in each PCT was designated to lead on EPP. For all 46 PCT leads, working on the EPP formed only part of their job portfolio. Their main role varied considerably, so it was not possible to determine if this had any impact on the success of the EPP. PCTs had access to members of the national EPP training team who acted as a resource to help run courses and raise awareness and who were appointed to salaried positions funded by the NHS. Teams of trainers were based in zones approximately co-terminus with the 28 NHS Strategic Health Authorities. All PCTs were expected to recruit and train at least two volunteer course tutors who would be supported and assessed by the trainers until they were accredited and considered capable of delivering courses on their own.

Recruitment to EPP courses occurred, in most cases, as a result of the zonal trainers working

Table 1 Policy context and expected outcomes

Policy Context	Mechanisms	Outcomes
Increasing levels of poorly managed long-term health conditions (Department of Health, 1999a; 2000)	EPP course – goal setting and action plans	Better patient involvement in care of long-term health conditions. Improved partnership working with GP
Disempowered, helpless patients (Department of Health, 2001)	EPP course – interaction/ comparison with others – a positive 'can do' experience	Participants feel empowered. Able to take on more responsibility for care
High costs of long-term health conditions (Wanless, 2002)	EPP course – instructions/ discussions on how to make best use of services	Improved use of health services – leading to decreased dependency and decreased repeat visits
Modernizing: changing workforce– innovation (Department of Health, 2002b)	Introduce new workforce – the EPP trainers and voluntary tutors	New workforce increases awareness of value of self-care
Increase public involvement in health care decisions at local level (Department of Health, 1999b)	New workforce. PCTs can utilize experience/views of those who have completed EPP course	Lay trainers and tutors provide links with community. PCTs have direct access to a section of the public with plenty of health service experience
Improve support/choice for those with long-term health conditions (Department of Health, 2002a; 2003)	EPP course – encourages participants to seek information and resources in community. Raises awareness of health care choices	Increased social capacity in community. Patients more aware of choices available and better informed as to their appropriateness.

closely with the PCT EPP leads. In a very few cases, the zonal trainers took on the full responsibility for recruitment strategy (in terms of advertising, awareness raising and direct contact with potential participants) with minimal input from the PCT leads. This approach was initially successful in terms of recruitment, but was likely to lead to PCTs becoming quickly disengaged from the programme.

Recruitment to EPP courses was used as a key marker of success in implementing EPP. Success was defined as completion of one or more courses and being on target for completing four courses by the end of the pilot phase. The PCTs where recruitment to EPP courses had been successful (just under a quarter of the sample) had the following general characteristics, they:

- were more likely to be in urban areas (one-third of successful PCTs were in urban areas, whilst under a fifth of the whole sample of PCTs were urban);
- were more likely to have developed a database of waiting lists for courses;
- had early access to three or more voluntary tutors (either because tutors previously trained in delivering the course were identified or because they made recruiting and training tutors an early priority);
- had a PCT lead who delegated administrative responsibilities;
- were more likely to be networking and sharing resources with other PCTs;
- had held an awareness day;

- had used local newspapers to publicize courses; and
- far more health professionals in these PCTs were reported to have shown some interest or been actively supportive of EPP.

PCTs where there were broad and flexible views of where the PCT roles could be linked to strategic policy goals, who invested energy in targeting specific groups, and who saw themselves as potential beneficiaries of self-care, had far fewer problems with recruitment (see Figure 1).

Recruitment strategies

A key task of all the PCT leads was to ensure that the EPP was advertised in their locality. The EPP was generally advertised by the date and venue of the next course and advertising often started several months before the course date. For half the courses in the survey, it took less than eight weeks to recruit participants. Courses were mainly advertised through leaflets and the local media, but in those PCTs where more than one course had been held, word of mouth was said to be one of the best ways of advertising courses:

> I'm saying there isn't one thing that helped advertising, but I think that would be it. The participants can sell it better than anybody else. And that has been quite powerful.
>
> ID 62 (Public Involvement)

A PCT with urban and rural areas, two courses have been completed and a third was in progress. The key driver for the PCT was to meet the public involvement agenda and a strategy is being developed within the PCT to take EPP forward. More than one day a week is devoted to dealing with EPP. An assistant to the PCT lead deals with phone enquiries from patients, explains the EPP course and maintains a database – they currently have a waiting list of 30 patients, so no problems getting participants and they have six voluntary tutors so are developing flexibility and independence in being able to put on courses.

The PCT lead has worked hard at exploring all forms of publicity and awareness raising and feels none should be ruled out, uses champions to promote EPP, e.g., nurses and PALs managers. GPs have not been engaged yet, next course planned in single practice so whole practice team can own the course and promote it. Meeting arranged at end of EPP course for PCT to have feedback from participants on general health service issues.

Figure 1   PCT invested time and effort to make EPP a success

From the accounts provided in the interviews there appeared to be an understanding of the need for awareness of the EPP at different levels within the local health community in order to ensure recruitment to courses remained sustainable. This included:

- At the level of the individual patient.
- The health care professional networks, and health and social care agencies.
- Within voluntary, community and patient self-help groups.
- At PCT level to link in with other policies and to get on the executive committee's agenda.

For some PCTs, the process of building up the awareness in the community was a considerable learning curve as this quote illustrates:

> We met with the local media, the headline in the paper was 'Pioneer Course Drug Free Pain Control'. Oh grim. Again, the lesson learned there was that we should have written our own articles. We met with another paper, they missed the phone number off. So again, totally unstructured the way we went around it. But it seems the big audience that we missed, because of course we were so focussed on the healthcare professional side, we'd no links with the voluntary sector whatsoever. Very fragmented in terms of advertising with the local supermarkets, cos we soon learned that posters were not going to get people there, people don't look at posters in GP surgeries, supermarkets or whatever. So again we learned the lessons about media involvement and how we wanted to communicate, and the best way, of course, is talking to local community groups, which we've built a structure around that now around local voluntary groups, around the community nurse forums and practice managers.
>
> ID 56 (Services Manager)

However, the need to increase and act upon awareness at different levels in order to make EPP succeed was not always matched by the appropriate action. Less than half the PCTs had taken action other than distributing paper information as the means of recruitment, sending flyers or leaflets to individual general practices and other organizations was the most frequently used strategy by all but one of the PCTs. At times this was perceived as a time consuming task with little or no perceived benefit in terms of patient contact or interest in courses. Health professionals and general practitioners (GPs) in particular were thought to just be ignoring the information. Many spoke about distributing posters and leaflets to places where people in the community would pick them up, such as libraries, supermarkets and pharmacies. Little attempt was made to audit the success of these approaches:

> I found it quite a large sort of paper exercise for such a small, we actually parted, gosh it's hundreds of places, got thousands of posters and leaflets and things for quite a small return, I suppose, of patients.
>
> ID 26 (Clinical Governance)

Using local media (e.g., the local newspapers or free papers) was tried by 35 PCTs as a way to raise awareness. Reports on the effectiveness of using the press varied from site to site. For most, this was a moderately successful way of raising awareness in the community. However, a few sites described problems where the PCT had little control over the content of the article, and where the final content was not an accurate representation of the nature or aims of the course. For example, a local reporter slanted an article towards helping back pain and people who responded to the article thought that coming on the course would cure them of back pain. Using the PCT communications department to write press releases was one way of retaining more control. Use of photos and articles about past course participants was a powerful way to advertise the course. Awareness raising events were generally successful when aimed at the whole local community. The days targeted specifically at health professionals tended to be less successful with poor turnouts. Awareness raising events were good for direct recruitment of participants and for engaging professionals, particularly where other professionals act as product champions (see Figure 2), but only when professionals can be persuaded to attend. However, health professionals who already encourage self-care are the most likely to attend such events, the real problem is that most lack the motivation or do not understand the need to find out more about self-care.

Failure to make links with key agencies and agents who are likely to have contact with patients with long-term health conditions was a probable

An urban setting, completed three courses with a waiting list of around 30 and four tutors.

Held a successful awareness day where PCT Chief Executive acted as a champion for EPP. The PCT lead has made personal contact with local GPs who are sending patients through. The GPs who were most supportive had heard about EPP at a national event (which gave EPP more kudos).

The PCT utilizes the expertise of participants by involving them in local public involvement initiatives, e.g., as the user representative on the diabetes development group.

Figure 2   Success in engaging health professionals

reason for many of the difficulties with recruitment. Indications of weak links were PCTs where the only contact was by post or through articles or announcements in internal newsletters. All PCT leads had attempted to make links with a wide variety of potential supporters of EPP, liaisons and links worked best when there was some form of personal contact, either because the PCT lead or trainer had already formed good relationships in the past with local GPs, health professionals, voluntary or community organizations, or where there was a key local GP or specialist acting as a champion for EPP:

I'd be a lot more happy if it came through first through the health professionals. Cos they're the people who see these people day to day. They're also the people who we're trying to wean these people off. They're the ones who best recommend courses, because in fact what you find with people is 'Well I'm not going to go onto that. I'm not even interested, I won't even acknowledge it, because I see my doctor every week'

ID 44 (Public Involvement)

There was good personal contact and engagement with voluntary and community organizations in just over half the PCTs. Contact proved especially helpful for recruitment in PCTs where there was knowledge about previous work of voluntary organizations in programmes encouraging self-care of long-term health conditions (e.g., the living well programme run by LMCA (Cooper, 2001)) or where local support groups were actively involved with local communities:

We've run a couple of awareness sessions locally which we pre-advertised through the

voluntary user group networks that we work with on a number of public involvement issues. And they were reasonably successful. They generated, if you like, specific group interest. That's been disseminated down to the members of those groups through the group lead that came on those awareness days.

ID 40 (Assistant Director)

Access to recruitment from secondary care services was perceived to be difficult. Many PCTs had not formed meaningful links with secondary care services because they saw EPP as being a purely primary-care-based initiative. Discouragement was reported from specialist staff already running disease specific courses. When talking to specialists, PCT leads felt at a disadvantage when trying to persuade them about the benefits of generic lay-led self-care support courses. Those who had made positive links with secondary care had done so through: existing connections with pain clinics, physiotherapists or occupational therapists, or specialist nurse contacts:

We've had sort of, discussions around it, but they've got issues with the actual scheme which I thought would be resolved once they knew more about it, but isn't. And a particular issue is that it's a lay delivery. I think there's sort of a little bit of professionalism and reluctance to it.

ID 55 (Public Health)

Table 2 is a result of the analysis of the interviews and presents a realistic evaluation of the actual context, proposed mechanisms and expected outcomes.

Table 2 Realistic Evaluation – in relation to recruitment for EPP courses

Context	Mechanisms	Outcome
Too many new initiatives from Department of Health	1) Health professionals unable to understand value or relevance of EPP, wary of lay-led course, wary of patients as 'experts'	1) Information on EPP ignored – patients not informed about courses
	2) Role of self-care for long-term health conditions explained	2) Viewed as additional support/ resource for patients
	3) Stress importance of experiential modelling in course	3) Lay trainers seen as resource
	4) Generic components of course – common experiences of living with long-term health conditions	4) Complement to but not substitute for technical disease specific education
PCTs do not feel ownership of EPP	1) EPP viewed as one of many administrative tasks, not seen as priority. Course content controlled by trainers – no input from PCT	1) Attempts to recruit course participants seen as paper-based exercise – poor response
	2) EPP described as community-based resource	2) Links formed with relevant and active groups in local community
	3) Relevance of EPP to national policies clarified and linked into PCT priorities and standards/targets	3) EPP given higher priority and more kudos by PCT executive committee. Better resources to help EPP administration
	4) PCT taps into course participants as a resource	4) Participants help raise awareness of self-care within their communities and to their health professionals – recruitment to courses increases

Discussions

There are a number of limitations to this study. No data was collected on the non-responders and it is not possible to say whether their experiences of implementation were better or worse. The 46 PCTs in this sample were all early adopters of a new innovation (Berwick, 2003), so it is likely they may be more willing and have the risk tolerance and resources to make new schemes work, it is possible that later adopters may have more problems in implementation. An equally valid view is that those involved in implementing the EPP at a regional and national level (the trainers) may learn from the experiences of the early adopters and be in a better position to advise PCTs coming into the programme later. The data presented in the paper is self-reported and respondents may have a self-presentational agenda, however, there is objective data on the number of courses run.

The proponents of realistic evaluation argue that contexts change so researchers can 'never expect to know "what works" but just keep trying to find out' (Pawson and Tilley, 2001: 323); there is a need to build on evaluations of past policies and theories. We will build on the findings of this preliminary survey as part of the full process evaluation of the EPP. However, this realistic evaluation does illuminate the importance of recruitment to courses to the success of self-care programmes and has helped to draw a picture of the types of people such courses work for.

The success of the initial implementation of the EPP can be assessed in relation to programme aims as set out by the aspects outlined by Nutbeam (1998). In terms of 'programme reach', as the programme is in the early stages the imperative was to recruit. In general, many PCTs struggled to fill the courses and current poor levels of recruitment are a threat to the viability of EPP as a part of the NHS delivery of user-led self-care courses. PCTs concentrated on general recruitment from their local area and few had attempted to recruit from ethnic minority communities and areas of high social

deprivation. Such areas were to be targeted once the administrative infrastructure had been established and, perhaps of more importance, once volunteer tutors from these communities had been recruited and trained as it was recognized that they would be better able to engage with their own community. The marketing strategy of mass leafleting and posters was intended to raise local awareness of the programme (both for the general population and for health professionals) but gave relatively poorer results than using carefully thought out radio and press articles. Such restricted marketing campaigns seem to have arisen because of initial concern about being swamped and not having administrative processes or personnel in place. Use of posters and leaflets probably fits very poorly with how patients and professionals can be engaged, this accords with the dearth of research evidence on dissemination (Berwick, 2003).

The cost to PCTs of running the pilot phase of the EPP was offset by a lump sum from the Department of Health and it was beyond the remit of this preliminary survey to analyse how this was spent. However, virtually all PCTs used cheap leaflets as a means of advertising and the major cost would be personnel time and involvement which did vary considerably.

Recruitment to date has occurred predominately as a result of direct contact with potential *participants* responding directly to adverts or leaflets. This fits with the ethos of self-referral which is stressed as an important component of some self-care support programmes. However, there is an inbuilt tension in the piloting of EPP within PCTs as it is viewed by many of its proponents as working best when it is delivered outside the medical model. GPs are not seen as a referral source for participants by the main proponents of the EPP (the national trainers) – their role is seen as identifying patients who might benefit from EPP and recommending the EPP to them so that they feel encouraged to contact organizers themselves. This may seem a relatively minor difference in procedure, but it relates to a large difference in philosophy. PCT leads originally interpreted this as meaning they only had to inform GPs about course dates, assuming they would pass on this information to relevant patients; there appeared to be limited early appreciation of the need for health professionals to be educated or the more fundamental change in culture needed to facilitate fitting self-care training into care of long-term

health conditions. Practitioners in primary care have regular and routine contact with those who have long-term health conditions and practice nurses are increasingly responsible for monitoring and educating such patients (Baird, 2003). Disease specific information is often given in the form of group education led by a specialist nurse or doctor; information is generally biomedical and disease focussed. It is recognized that there are a number of barriers to health professional involvement in promoting and supporting self-care, for example, it is perceived as a challenge to professional expertise (Thorne *et al.*, 2000) and there is evidence that professionals discount experiential knowledge (Paterson, 2001).

PCT leads acknowledged that GPs are overworked and often inundated with new schemes. They may not take EPP on board until they see that it is an enduring programme. Nonetheless given the extensive access that health professionals have to people living with a long-term health condition and who would benefit from self-care, efforts to raise awareness of the benefits of the programme and attempts to actively engage those within health and social care agencies are likely to become increasingly important in recruiting the harder to reach people. It seems probable from evidence, for example, that the more affluent and educated make more use of resources such as the Internet (Mead *et al.*, 2003), that the more assertive and confident who may have already been familiar with self-care principles will be motivated or familiar enough to engage independently of prompts from elsewhere. However, in the absence of mediation, endorsement or raising awareness by professionals, there is a risk that the more diffident, less assertive people with long-term health conditions will be unlikely to access this resource.

So, in terms of programme acceptability to the target population, it seems important to engage health professionals with the ethos of the programme, once they understand the value to their patients of a lay-led experiential course which is complementary to and not a substitute for disease specific education, they may be more prepared to recommend the EPP and be more active in helping those from hard to reach communities get on a course (see Table 2), although we lack the evidence to support this.

In terms of the third aim of programme integrity and implementation at PCT organizational level, the EPP was not seen (by those charged with its implementation) as having a direct meaningful target to

meet (such as linking to the self-care guidelines in NSFs or to public involvement strategies), but only the very basic and pressing need to fill course places and run four courses during the pilot years. This may have resulted in a lack of commitment by many PCT leads who, since administrating the EPP formed only part of their work portfolio, spent most of their time dealing with what they considered to be other, more urgent, priorities. PCTs whose leads were in a position to be able to delegate administrative responsibility were more likely to be successful in recruiting to courses. The restriction of marketing strategies to sending out leaflets and requesting GP practices to put up posters may have stifled potential demand. Giving EPP a higher profile in the business of PCTs at board level and focussing on its value as a community resource may ensure future sustainability (see Table 2). Clearer links to the strategic goals and agendas of the NHS such as the NSFs or public health at Department of Health policy level might encourage a view in PCTs that EPP is a central plank of NHS practice and policy.

Acknowledgements

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