Self Care Support:
Baseline study of activity and development in self care support in PCTs and local areas

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Key messages

Self care support in PCT organisations:

- There is a substantial amount of work going on at PCT level to support self care. This work ranges from health improvement / prevention through to support for long term conditions.

- Interpretations of what 'self care' means currently varies both within and between PCTs. There needs to be a better shared understanding of the scope of self care and PCTs need to take an integrated approach to self care support.

- Some PCTs saw self care as a key component of the case management agenda. Others felt that only the Expert Patients Programme was an essential part of support for self care.

- Many PCTs were providing support for self care but either it was disjointed and not well organised with different initiatives not known to each other or much of the work being done was not badged as self care.

- In most PCTs work to support self care is not connected through a formal PCT plan or strategy, nor across PCT internal working structures.

- Most PCTs did not have a specified lead for self care and often did not see the need for one.

- Self care was reported only in some cases in relation to PSA targets or within LDPs but many PCTs identified ways in which self care could contribute to meeting targets.

PCT activity to support self care:

- There were many examples of innovative work to prevent ill health and to improve health in most PCTs.

- There was less activity in the area of minor ailments, with the exception of community pharmacy minor ailment schemes, which were in operation in several PCTs.

- Activity in relation to EPP was highly variable, with a range of 4 to 20 courses planned for the next year.

- Some PCTs had forged strong partnerships with local organisations including schools, employers and community groups and described various innovative self care support programmes.

Engaging health and social care professionals in supporting self care:

- Awareness of the scope and potential for self care among care professionals was perceived to be, at best, patchy.

- Little training on self care had been provided so far for care professionals, although several PCTs identified this as an urgent need.

- PCTs had little information about referral by health professionals to local self care support programmes but thought it to be variable. EPP leads generally reported that word of mouth was the main source of recruitment for their courses.

Possible risks of supporting self care:

- Few PCTs appeared to have systematically considered potential risks of supporting self care. However most PCTs articulated some risks in supporting self care. These risks related to the public and to the NHS.

- The main perceived risk to the public was delayed consultation with health professionals and resulting adverse effects on health.

- The main organisational risk cited was the potential, at least in the short term, of increased demand for resources, particularly for preventive / health improving services from people with long term conditions.

- Other identified risks included the potentially resource intensive nature of self care and self management skills training and of sustaining self care support networks of lay/peer volunteers, as well as a perception that health and social care professionals needed greater awareness of self care.

Future plans:

- The most frequently cited plans involved developing disease specific components of self care and self management skills training, and using the new community pharmacy contract to achieve greater involvement of local pharmacies in supporting self care.
- There appears to be a risk of duplication and reinventing of work in developing a range of disease specific programmes.

1. Background, Aim and Objectives

Background

A national strategy for self care support is being continually developed and the importance of achieving sustainable self care support networks across health economies is recognised (Self Care - A Real Choice, Self Care Support - A Real Option, DH 2005; Supporting people with long term conditions, DH 2005). A previous report identified and described examples of existing innovative practice in supporting self care across the whole system of health and social care (Self Care Support Compendium, DH 2005). The purpose of the current work is to provide baseline data on self care support activity in PCT areas. The intention of the work is to drill down into individual local health economies to scope the existing and planned level of activities in self care support, and PCTs' approaches to developing this area of work.

Aim

The principal aim of this study is to map the types, level and co-ordination of self care support activity in PCT areas.

Objectives

The key objectives for a random sample of 5% of PCTs in England are to:

1. Identify key informants who are leading on self care support.
2. Design a data collection method to gather information on existing and planned self care support in randomly selected PCT areas.
3. Elucidate the ways in which PCTs are conceptualising self care support and their approaches at strategic and operational levels.
4. Produce a report on key themes from the PCT data to describe and interpret the current situation in relation to self care support.
5. Propose a set of key indicators and chart these across the sample of PCTs.

2. Methods

A random sample of 15 PCTs (5% of the national total) was drawn using a random number generator set from 1-300.

The initial sample of 15 PCTs was reviewed to consider the mix of socio-demographic features and it was felt that the sample represented an appropriate range. The next five PCTs were also identified to allow for non-participation by some PCTs in the original sample.

The random numbers, PCTs and their participation are shown in Appendix 1.

An internet search was conducted for each PCT to scope examples of self care support activities and plans. The search included the PCTs' own websites, the NatPaCT site and use of a search engine. This initial information was tabulated to provide background information for the subsequent data collection. It was possible to identify some key contacts from the preliminary research and these included staff in Patient and Public Involvement and in Public Health. Initial contact was made with an individual from each PCT, describing the baseline study, and seeking participation in an individual interview plus identification of other relevant contacts for follow up.

Data were collected between November 2004 and February 2005 using telephone interviews and a structured interview schedule. The areas investigated included:

- Types of self care support provided by the PCT
- How the PCT works as an organisation to support self care
- Involvement of local health and social care professionals in supporting self care
- Partnership working with local organisations for supporting self care
- Risk assessment
- The future

The data collection method was piloted with a PCT outside the study sample, with the key informant being a Public Health Specialist. The pilot confirmed that it was likely that a minimum of two interviews would be needed for each PCT to cover the required areas. An initial contact was made for each PCT, usually with the DPH. The list of interview topics and a chart showing examples of self care support were emailed to the initial contact. Subsequently interviews were conducted with the initial contact and/or other individuals nominated by them.

Securing the telephone interviews often involved multiple emails and telephone calls, probably reflecting the workload of PCT staff. Initially one PCT declined to participate (Dartford) because they were in the process of implementing a recovery plan and the PCT had decided not to participate in any non-essential activities. The next PCT from the sample was added (Central Suffolk). Subsequently a second PCT declined to participate (Newcastle-on-Tyne) because several key posts were vacant and workload pressures were felt to be too high. Despite numerous contacts and a booked interview time it proved not to be possible to interview the contact from Central Suffolk and one contact each from North Tees and Uttlesford due to their unavailability. In three PCTs,

the initial contact obtained information from other colleagues prior to the interview and was able to cover all of the interview topics.

In total 27 of 28 booked telephone interviews were completed and two respondents provided information by email. The total number of respondents was thus 29. The PCTs and respondents are listed in Appendix 1. Individual interviews lasted between 20 minutes and one hour and the average interview time per PCT was around one hour 15 minutes. Detailed notes including verbatim quotes were taken during each interview.

In the 'Findings' section that follows both quantitative and qualitative data are presented. Summary charts are of key indicators. Quotations from respondents are used to illustrate key themes and the PCT is identified by a code letter. Illustrative examples of self care support activities and development are included and the relevant host PCT is identified.

3. Findings

3.1.1 Key indicators

A draft set of key indicators for PCT support for self care was compiled and applied to the data. The indicators were selected to represent: strategic approach to self care (columns 1-3); extent of peer/lay led support (columns 4&5); and supporting people in relation to minor ailments (column 6). Finally, the PCT's own rating of progress in self care support was included (Column 7). The findings are charted in Table 2 below.

Table 1: Summary of Key indicators

PCT	Self care strategy	Self care lead	Self care in LDP	Number of EPP courses planned	Other lay / peer led schemes	Pharmacy Minor ailment scheme	PCT's self-rating on progress
A	×	√	×	6	√		Average
B	×	×	×	6		√*	Average
C	×	×	×	19	√		Average
D	×	×	×			√	Below average
E	×	×	×	3			Below average
F	×	×	×	4	√	√	Above average
G	×	×	×		√	√	Average
H	×	×	×	Not finalised		√	Average
I	×	×	×	3	√		Above average
J	×	×	×	5-6			Below Average
K	×	×	×	Not finalised		Pilot	Average
L	×	×	×		√	Under consideration	Above average
M	×	×	×	4			Above average

* Minor Ailment scheme covers head lice only

3.1. 2 Level of activity supporting self care

The sample PCTs were engaged in a substantial amount of work on supporting self care. Most of the activity was reported around prevention work and around self care support for people with long term conditions.

A systematic approach for supporting people in relation to minor ailments was the area least well covered by current PCT programmes.

"Minor illness isn't really featuring as a key action area." (PCT A)

"We're doing very little on common ailments – other than some leaflets." (PCT J)

There were exceptions to this, including community pharmacy minor ailment schemes (MAS) which were in place in several PCTs. Other work was being done as part of the Primary Care Collaborative programme on advanced access.

"The GPs filled in a tick sheet as to whether the patient needed to be seen by them, whether they could be seen by another health professional, or if the patient could have done self care. When we fed the results back to the GPs they were surprised by the high numbers they didn't need to see." (PCT C)

3.1.3 Organisational approach to self care in PCTs

The main themes here were:

- Self care featured in several work programmes within PCTs and was rarely the subject of an overarching strategy
- Some PCTs had identified a need to develop a more strategic and joined up approach to self care in the future
- Most PCTs did not have an identified lead on self care
- Self care was generally identified most closely with the long term conditions work programme and was a sub-set of that in some PCTs

One of the PCTs had an overarching strategy for supporting self care. The others did not have a specific strategy and described how self care featured within individual work streams.

"Not specifically on self care but self care is a strand in other strategies - Primary Care and so on." (PCT B)

"Not on self care itself but lots of different strategies that include self care." (PCT E)

"There's no earmarked strategy for self care." (PCT A)

"Part of our PPI strategy is an obligation to involve patients in their own care." (PCT G)

The three main directorates in which self care activities featured were **Public Health, Patient and Public Involvement and Primary Care**. Individuals responsible for Operational Services, Patient Services and Service Improvement were also mentioned by some PCTs. Some PCTs specifically mentioned **Nursing Directorate** in the context of specialist nurses working with long term conditions.

"The main people involved are in public health, some primary care and also our PPI person who leads on EPP." (PCT M)

Some of the PCTs' accounts indicated a recognition that work on self care needed to become more **integrated**:

"We need to get loads smarter at integrating this work. There's lots going on but we've all been doing it in our silos." (PCT H)

"There's a huge amount around lifestyles, CHD and so on, but not integrated." (PCT K)

"There are all sorts of initiatives but not in a coherent way to deliver a package." (PCT J)

As one of the participants put it:

My impression about self care is that most PCTs (including my own) are just beginning to address self care in a systematic way to support long term conditions." (PCT J)

One of the PCTs reported having a director leading self care.

"The PCT has a Director level lead . . the person also responsible for NSFs." (PCT A)

In the other PCTs several posts included an element of self care.

"Several people have responsibility for self care – mainly those responsible for certain population groups, for example the Older People lead." (PCT E)

Long term conditions leads and Service Development / Improvement leads were also reported to be key in relation to self care support and although not formally designated as the lead on self care, was perceived as such in one PCT.

"Self care is a sub-programme of the long term conditions work." (PCT J)

"I wouldn't see myself as the lead, but kick starting." (PCT H)

Some PCTs had recognised that a lead might be needed. One reported:

"There is no clear lead but we recently identified a need for a lead on this and it will be from primary care." (PCT M)

Two of the PCTs described how the need for links between EPP and supporting people with long-term conditions were driving a different way of thinking about self care.

"We're bringing together our EPP programme with our work on care of people with long-term conditions. We have a Special Interest Group and strategy group on LTC." (PCT M)

3.1.4 PCTs' perceptions of progress in supporting self care

The PCTs were asked, in relation to supporting self care, whether they would say their PCT was ahead of others, average or behind others. Respondents' answers showed that PCTs were at different stages in the development of their thinking and plans for self care. Some were at an early stage:

"There's a lot of talk going on about it . . . dealing with it condition by condition." (PCT D)

"I don't think we're ahead – there's a lot of work to be done." (PCT J)

Some recognised that while they had made **progress at operational level**, more work was needed to develop a **strategic approach**:

"Where we'll be behind is that we haven't looked at it from a strategic perspective." (PCT H)

Most PCTs regarded their progress in developing support for self care as being about the same as others:

"About average. We have an obligation to demonstrate evidence and outcomes of what we are doing on self care rather than have some huge structure." (PCT G)

"A long way off but we're getting there." (PCT C)

Others regarded their progress as being ahead of others, even if only slightly:

"In terms of our PPI strategy and work on the ground I'd say we're marginally ahead of others." (PCT M)

"I think we're ahead of others." (PCT I)

"Probably not streets ahead but making inroads." (PCT F)

To benchmark their own progress, PCTs tended to compare themselves with other PCTs in their SHA.

"Within our SHA I'd say we're about average." (PCT B)

"I'd say we're similar to other PCTs in our area – some examples of relevant work but ***challenge in bringing it together****." (PCT A)*

One PCT commented that their relatively slow progress in the past had largely been due to a lack of input from service users:

"We currently don't have a PPI role – we need to invest heavily to get PPI right and involved in service design at the earliest stage." (PCT E)

3.1.5 PCT culture in relation to self care support

Respondents were asked how they would describe the culture of their PCT as an organisation in relation to self care support. Some respondents reported that there was both an **increasing recognition of the importance of self care** and a drive to move forward:

*"The PCT is receptive and wants to develop self care. The people who hold the purse strings now understand the **need to invest in self care** to save money." (PCT J)*

The concept of the pyramid of care had clearly become embedded in the thinking of many PCTs. The spread of the concept of case management seemed to have reached all of the PCTs and this in turn appeared to have raised the profile of self care through awareness of its presence within the pyramid:

*"Becoming more and more aware . . . seeing the triangle – the full range of activities that is needed . . . a **commitment to get involved in self care**." (PCT B)*

Other PCTs appeared to be at the stage of contemplation of what they might need to do to support self care, with awareness that action would be needed soon:

"Thinking, thinking, thinking . . a major effort this year." (PCT J)

Some respondents described their PCTs approach as more slowly evolving, taking opportunities where they arose:

"Very supportive – not driving but developing opportunistically." (PCT M)

*"It's **part of a growing culture** rather than an existing culture." (PCT E)*

Other respondents seemed to be less convinced of the benefits of self care, with awareness of some but not all of the supporting evidence, and a culture where there was an **expectation of rigorous evaluation** of new initiatives:

"Well the evidence around self care seems to show that it keeps people out of hospital." (PCT D)

"We're strong on evaluation." (PCT G)

3.1.6 Self care in the LDP and in relation to PSA targets

The PCTs did not specify self care explicitly in their LDP or in relation to PSA targets:

"There may be slight connections but (self care) hasn't really featured. I'd like this to be strengthened." (PCT A)

Some clearly described the possible links:

*"We're piloting three models of case management. In the Older People section of the LDP for example we've included a joint post with social services that will relate to our Falls Strategy and in turn to the **independent living** targets." (PCT E)*

*"Some measures in our LDP, for example, smoking cessation and breastfeeding . . . in terms of PSA targets – **more people, more active**, more often." (PCT I)*

"Cancer and breastfeeding – but not consciously linked to self care." (PCT G)

*"**Emergency admissions will not be reduced without self care**." (PCT J)*

*"Initially our long-term conditions agenda was to reduce unplanned admissions – our PCT was in the top five for this – now we're **ready to move on to strategy to support self care**." (PCT B)*

These data suggest that while LDPs may not explicitly refer to self care, PCTs recognise some of the areas where self care can contribute to LDP priorities. One respondent reported that in their LDP discussions self care had become prominent:

*"**Self care is a priority in our LDP process**." (PCT H)*

3.1.7 Risk assessment

Most respondents did not know whether their PCT had systematically considered whether there were risks of supporting self care, although some respondents referred to routine risk assessments. However all of the respondents cited possible risks of supporting self care. The most commonly cited risk was that in encouraging patients to self care, timely help might not be sought when it was needed or that there may be an increase in demand for care services.

"It's a balance – individuals undertaking self care versus their not seeking help when needed." (PCT E)

"There may be a direct risk to patients when we encourage them not to see the doctor – for example missing serious symptoms." (PCT I)

"Patients not recognising when they need help." (PCT B)

Respondents also expressed views about how potential risks could be managed.

"If self care is not properly monitored some patients may not present when they need to . . care needs to be proactive and people with long term conditions need to have a personalised action plan." (PCT J)

"The issue is that we need to give people proper guidance and skills to know when their illness is deteriorating – markers to recognise when medical intervention is required." (PCT H)

"Managing the risk is about case managers identifying their population and supporting individuals differently." (PCT E)

Some respondents identified conflicting messages as a possible risk:

"We need to raise the capabilities of health professionals to pass on consistent messages to patients . . . there's a risk of people saying different things and damaging patients' confidence through conflicting advice. Health professionals need to know the evidence and they need to know how to tap into voluntary and community organisations locally." (PCT M)

Managing this risk would require agreement on a unified message:

"We need to articulate what is good practice in promoting self care." (PCT C)

Other, more specific risks had been identified when changing methods of service delivery and/or organisation. In the example below the PCT had introduced Patient Group Directions to enable nurses to supply certain treatments within closely defined circumstances:

"There were some risks around changes in access . . due to introducing Patient Group Directions for nurses." (PCT M)

One respondent felt that there was a risk that there would be a limited uptake of self care by the public:

"We need a culture change among the public – some families are keen to embrace self care but others are very dependent." (PCT E)

Three PCTs mentioned risks relating to resources. In the first case this related to the long term nature of activity needed to produce benefits from health promoting work, especially in a context where PCTs needed to deliver on other areas in the short to medium term such as reducing hospital admissions.

"Investing in prevention needs disinvestment from treatment." (PCT C)

"Case management will not succeed if other events are not addressed downstream - obesity, nutrition, physical activity." (PCT J)

In another PCT, which had an active and expanding programme of peer mentors, there was a perceived risk of underestimating the resources needed for volunteer programmes:

"Capacity to support peer mentors, update and sustain them." (PCT G)

In particular the need for **regular updating and training** to ensure that peer mentors were providing accurate information was seen as an issue. In this case the PCT hoped they would be able to mobilise volunteers:

"Support from health professionals on content accuracy and deliver training support using local people".

Resource consequences of increasing self care support, for example encouraging people with long term conditions to participate in prevention programmes were also perceived as a risk.

3.1.8 Information on uptake of self care support resources

The PCTs in the study did not keep information about uptake of most of the self care support resources available locally, with the exception of the EPP. When asked about numbers of people being referred to by GPs/nurses, or self-referring, to resources or services most PCTs had little information. There were some exceptions, for example Slough PCT kept records of activities of its Health Activists. However in general, monitoring of referral and uptake appear to be areas where further development is needed.

3. 2 Partnership working

3.2.1 With employers, local businesses and voluntary & community agencies

Four PCTs had substantial partnership working with local employers.

Slough PCT has a joint appointment with MIND and is working with local employers using 'Under Pressure', a training pack developed locally with East Berkshire Mind. The session is aimed at managers and employees. It raises awareness on issues around **stress** and provides information about available support. The PCT also has a '**Heartbeat Award**' programme which they adapted to "Catering for Health". Local businesses and catering establishments are able to complete a **web-based assessment**.

South and East Dorset PCT has a '**Health at Work**' programme with public and private sector employers. Areas of activity include **stopping smoking, weight management and physical activity (group exercise sessions)**. The PCT employs a Lifestyles Manager who oversees the programme.

Darlington PCT has recently appointed a Workplace Health Manager. Pilot work is at the planning stage and intended areas include: **mental health well being; food at work; physical activity; smoking; drugs and alcohol; and breast feeding**. The areas covered by individual local businesses will be negotiated and agreed. Three stages of work are planned – Stage 1 will mainly comprise provision of information, Stage 2 will involve the development of activity to support workplace health. Stage 3 will work towards integration of a **sustainable healthy work ethos** into the organisation. The PCT had previously done some work on primary prevention of diabetes with representatives of local employers.

In South Sefton six local employers appointed a leader for the "Sefton Five" project to increase amounts of fruit and vegetables eaten and to increase daily activity by working towards walking 10,000 steps a day. Each leader was trained in motivational interviewing and key messages. A peer competition element was introduced into the scheme with points awarded, anonymised league tables for activity in the six employing organisations, and rewards. A session was held for local businesses called "Positive Working" with 70 attenders. A manual was produced for employers with information on **stop smoking services, nutrition and canteens, and workplace stress**.

One PCT had made approaches to employers and was about to begin some joint working:

*"We're starting to develop in this area. Our **Health of Men** programme is moving into local employers." (PCT I)*

In the other PCTs working with local employers was relatively undeveloped.

"This is an area where we're weak at the moment." (PCT E)

"Nothing so far with employers." (PCT M)

3.2.2 With schools

Five PCTs reported substantial programmes of work with local schools.

A mental health promotion pack, '**Feel Good, Stay Healthy**' was developed by Slough PCT, initially with primary schools, and is now being used with secondary schools. Six schools contributed to the pilot version. There is a pack for teachers to use in PHSE (Personal, Health and Social Education) classes and a guide for children and teachers. The content was based on research with young people and has a focus on risk factors

and protective factors – building self esteem and assertiveness, decision making, managing anger and developing emotional intelligence.

Newcastle PCT is one of eight working in partnership with LEAs in the Staffordshire and City of Stoke on Trent '**Health Promoting Schools Scheme**'. The PCT has funded refurbishment of areas within schools to become drop-in centres (Multi-Agency Centres - MACs). Local organisations attend the schools to provide advice on areas including sexual health, mental health and carer support. Work has also been undertaken with the Borough Council to educate and inform young people about drugs including 'What's your poison' – educational sessions which have been piloted in two local high schools, employing a detached recreational youth worker to speak to teenagers in known drug 'hot spots' , and a **drama-based project** involving four Chesterton schools.

School nurses run an 'Extended Schools' programme in one locality in North Tees involving one to one sessions with children with **long term health conditions** in addition to drop in clinics for **stress management and wider health promotion** activity. The PCT plans to involve district nurses and extend the programme to include other schools.

South and East Dorset has a **peer education** programme in some of its schools with a focus on sex education and drugs education. Peer Educators (PEs) were trained who delivered education in break time and after school. It is hoped that the programme will be expanded to include stopping smoking building on the research work in Bristol and Cardiff. Emerging issues have included individual PEs' time to support the programme and demands on their time.

As part of its Healthy Schools programme South Sefton PCT cascades training from **parents to parents on drugs/substance** misuse and sexual health. A project was developed with primary schools for children to **learn about heath services**, with visits to a GP practice, pharmacy, dentist and optometrist.

3.2.3 With leisure centres/facilities

Several PCTs mentioned '**Exercise on Prescription**' schemes involving local leisure centres. One PCT reported:

*"**All our local leisure centres are involved**. But it's not necessarily reaching people with more serious long term conditions. It will need more medical input . . . there's a nervousness about people with long-term conditions." (PCT A)*

Several PCTs offered a mix of resources for physical activity using local exercise facilities and outdoors activities. Havering PCT, for example, had a **GP exercise referral scheme**, falls prevention classes and a "**Walk for Health**" scheme. Older people had been invited to contribute to a consultation on **Active Ageing** and a booklet was produced including their ideas.

3.2.4 With local Councils

The PCTs were actively engaged in Local Strategic Partnerships and some mentioned joint work with local Councils.

Newcastle-under-Lyme PCT is co-located in the same building as the Borough Council and Social Services and this was reported to have facilitated joint working. Outputs included an **Environmental Heath** post partly funded by the PCT with a remit to manage a programme of awards for local restaurants, a joint programme on smoke free public places, and work with local schools (see above).

3.3 Specific Community based self care activities

3.3.1 Peer mentoring programmes

Six PCTs reported having at least one local programme involving peer health mentors/educators and two had substantial activity in this area.

PCT	Examples
South and East Dorset	Peer sex and drugs education in schools; also mixed age community focus groups to share information about healthy eating on a budget (a form of cross-generational teaching).
Newcastle under Lyme	'Mum to Mum' peer supporters including one-to-one and group support; a call centre; and volunteer peer support training developed in partnership with health visitors, midwives and the Newcastle Sure Start programme.
Slough	Health Activists in CHD. Currently 32 trained and active, providing information on CHD to ethnic minority communities with high CHD risk. Programme currently being expanded.
South Sefton	'CLIPS' project involving barbers and hairdressers in the most deprived areas of the PCT. Staff participated in training and then provided information packs on cancer. Several peer mentoring programmes including in Healthy Living Centres and Breastfeeding Peer Supporters.
Bradford South & West	**GP referral to community workers** to conduct interview/ consultation (**social prescription**). Peer tutors in Healthwise (formerly Look After Yourself) groups.
Tendring	Peer sexual health educators in schools. Parent volunteer programme (Sure Start). Trained volunteers supporting breastfeeding. Encouraging ethnic minority groups to identify community leaders.

In South and East Dorset links were made between Sure Start and older people through a Community Action worker. Older people were keen to participate in education of younger people. A programme on food and nutrition was developed for local schools in

which a **local greengrocer** was recruited to demonstrate healthy food and discuss costs, and also to arrange delivery of vegetables to people's homes. Older people became involved in teaching sessions in schools about food and nutrition. In return the schools offered **access to classes on IT** in which older people learned alongside the school students.

Slough PCT has an active and expanding **Health Activist** (HA) programme. In its first phase the HA work was with local ethnic minority groups with high CHD rates. Following the success of the early programme several new developments are taking place with more HAs, with work on mental health and also with older people. In a pilot project with GP practices HAs will be trained in weight management and patients will be referred to them from the **CHD register**. HAs will also be trained as **Community Needs Assessors** and will be attached to local Partnership and Service Planning Boards. The PCT's vision for this work is:

"Where we want to be is a tranche of HAs working with each PCT programme." (PCT F)

Recruitment of HAs has been wide-ranging. There were 60 applicants for the first wave, of whom 21 were selected and 18 completed training run by the local college network. A second course resulted in a further 14 HAs. There were 50 applicants for the third course and promotion with Age Concern among those working with older people has resulted in participants working in **residential care homes and neighbourhood wardens**. The HAs are **sessional workers** for the PCT and are paid for planning and running each of their sessions. At the end of the first phase 1,390 people had accessed healthy lifestyle messages through 87 sessions run by the HAs and evaluation showed **changes in knowledge and behaviour**. Alongside the training for HAs, 22 **health professionals** attended a workshop on CHD and **mentor training** is to be provided to support the HAs.

In the 'CLIPS' project in South Sefton, **barbers and hairdressers** in the most deprived areas of the PCT were invited to participate in a programme to deliver information about cancer risks and **healthy behaviours**. Staff took part in a training programme on site and then asked clients if they would like an information pack. The sites were visited regularly by PCT staff and an evaluation was undertaken with staff and clients.

"It was a good way to reach people who were not sure where to go for information and perhaps were not ready to ask." (PCT G)

The project is currently being rolled out. The PCT has several programmes involving peer mentors. Breastfeeding Peer Supporters was developed with Sure Start using the **national pack on peer mentors**, supported by community midwives and neighbourhood public health nurses. The PCT also has a peer mentor programme within its Healthy Living Centres. The volunteers are aged between 18-70, and participate in training (for example on cancer prevention, men's health). They have a directory of contacts for further information and referral. Sixty volunteer walk

leaders have been trained for the "**Walking the Way to Health**" programme. They are supported by a co-ordinator (a joint post with the LA and responsible for walking and cycling programmes) and have been involved in developing new walks to widen participation, e.g. pram ramble, historic walks. Local people are involved in a "**positive reminiscences**" programme in the Healthy Living Centres, where they lead courses in local history. The PCT has three 'Food and Health' workers associated with schools, employers and communities and working with groups. There is a strong commitment to peer support:

"Providing they are given the correct information and support it's better for people from the community to do this . . their friends and neighbours will ***find it more credible****." (PCT G)*

The PCT had encouraged some of the peer mentors to participate in intermediate level training for stopping smoking but found they were not confident to run sessions. These peer mentors are now shadowing others to develop confidence.

Tendring PCT had focused its work on the needs of parents and children, with peer programmes in schools and with Sure Start centres.

3.3.2 The Expert Patients Programme

Data on EPP were available for 10 PCTs, all of which had run generic EPP courses and one was currently running a generic course with a disease (diabetes) specific module.

Some PCTs reported successful EPP programmes, while others were more circumspect and reported difficulties in recruiting people with long-term conditions to participate. To some extent this appeared to depend on the amount of time the EPP lead was able to allocate. In one PCT a volunteer was working one half day per week to assist with the EPP programme.

Patterns of referral into EPP were variable. Word of mouth was generally considered to be a key element. Few PCTs reported substantial numbers of referrals from health professionals. In North Tees most referrals had been from the community mental health team.

There were examples of proactive engagement with local health professionals and with local communities. In Newcastle under Lyme for example the EPP co-ordinator (who combines this role with PALS Manager) had visited GP practices and had also established a concordat with the Local Pharmaceutical Committee so that pharmacists would promote the courses. In the same PCT an agreement had been reached with a local sheltered housing scheme following a successful pilot course run in one of its premises. The sheltered housing company had subsequently agreed to provide venues free of charge in its 19 sites during the next year. One pilot course had been run in a local GP practice. The environment was not as conducive as previous venues but this did not prove detrimental to the course as 2 of the participants went on to become volunteer Tutors.

EPP Courses run and planned in sample PCTs

PCT	Courses run to date	Courses planned for 2005-6	Future plans/comments
A	5 (64 participants) + 2 more in 2004-05	6	Courses already run included a course for young people.
B	7 (70 participants)	6	3 volunteer Tutors trained. Will include common mental illness specific session. Clinical Psychologists keen to refer to EPP.
C	4	19	9 volunteer Tutors trained. Collaboration with local sheltered housing company.
E	1 (1 cancelled due to low numbers)	1 currently running plus 3 in next year	3 course fully booked without advertising. 1 volunteer Tutor trained.
F	2 (25 participants) (1 cancelled due to low numbers)	4	2 volunteer Tutors trained. Working with 2 other PCTs with 12 courses planned in total. 2 courses to be run in Hindi and Punjabi.
H	3 (24 participants) 2 cancelled due to low numbers	Under discussion	Plan to link to agenda for supporting people with long-term conditions from March 05.
I	4	3 (Jan-Apr 05) Under discussion for 2005-06	Courses commissioned from Arthritis Care. 1 volunteer Tutor trained.
J	5 (80 participants)	5-6	PCT Operational Board recently approved a post of EPP co-ordinator and course funding.
K	4 (50 participants)	Plan to 2007 currently under development	Disease specific work with local HIV/AIDS voluntary agency. Developing additional session on medicines. 2 volunteer Tutors.
M	2 (24 participants) 1 more in 2004-5	At least 4	Planning to look at disease specific sessions.

In Bromley contact had been made with the majority of GP practices through visits either to a practice meeting or a meeting with the practice manager. Channels to promote EPP included local pharmacies, physiotherapists (with whom a meeting had been held), and hospital outpatients.

Some PCTs commented on their relative ease or difficulty in having course participants to come forward to train as volunteer Tutors.

"The courses have been really successful, enthusiastic people who very much got into leaning about their own health and helping others . . . but less comfortable with being asked to be Tutors." (PCT I)

In one PCT there had been considerable interest and four course participants had expressed interest in becoming volunteer Tutors. However financial circumstances had precluded it in three cases, two of whom were single mothers and a third had recently retired and needed to find paid work.

Some PCTs were actively working with neighbouring PCTs to share learning about effective methods of promoting the courses and to co-ordinate dates so that courses did not run concurrently and there was at least the possibility of cross-boundary attendance.

"We have a co-ordinators meeting with 6 co-ordinators to share ideas." (PCT J)

"Working with two other PCTs over the next year to reduce overlap between dates. There will be 12 courses offered to patients across the area of the three PCTs." (PCT G)

3.3.3 Disease specific programmes

Two PCTs reported running professional-led disease specific sessions along with the generic EPP course.

South Sefton has a community based diabetes team and patients have telephone access to support from diabetes nurses in the community (HImP News 2004). Newly diagnosed people with Type 2 diabetes are offered a 'Diabetes and You' half day group education session. The sessions comprise up to 20 participants with input from a diabetes nurse, GP, dietitian, podiatrist and a volunteer from the local Diabetes Support Group. The PCT is also running a pilot programme on COPD where patients receive educational sessions in their home (4) and in small groups in secondary care (4 sessions).

Newcastle-under-Lyme has been working on implementing group education sessions for people with diabetes and people with COPD. The diabetes programme is about to be piloted with a local practice.

3.3.4 Self care support for people in relation to minor ailments

Some of the PCTs had a community pharmacy minor ailments scheme. National policy here, as set out in 'Building on the Best' in late 2003, encouraged PCTs to consider a targeted scheme in disadvantaged areas. However PCTs were also responding to local circumstances.

Taunton Dene PCT focused its scheme on conditions that could otherwise only be treated by the GP. Their reasoning was that as a result of nGMS, practices were closing on Saturday mornings and with the shift to out of hours (OOH) providers here was a concern that attendances at A & E might rise for common conditions:

"We wanted to engage the majority of community pharmacies where potentially patients might call OOH or go to A & E." (PCT D)

Therefore all of the 18 local pharmacies were invited to participate (and all did so). The PCT had considered the list of the commonest conditions that were the subject of calls to NHS Direct (conjunctivitis and urinary tract infections were in the top 10) and also

consulted locally about which conditions to include in the scheme. The PCT plans to extend the scheme and is currently in discussions with the OOH providers and A & E about commonly presenting conditions that could be managed in pharmacies.

South Sefton's minor ailment scheme was the first in the UK and was the subject of an academic evaluation. Twelve conditions were initially included and the **transfer rate from GP to pharmacy consultations averaged around 40%**. The scheme now operates across the whole PCT.

3.4 Involving Professionals and the public

3.4.1 Engaging local health and social care professionals in self care

Most PCTs were at the stage of working through their own plans to support self care and they reported little activity to date in proactively engaging local health and social care professionals. However there was a recognition that this needed to occur because the PCTs' assessment of awareness of their local health and social care professionals about self care was variable. There were some specific conditions where health professionals were thought to be well aware of related preventive activities:

"GPs and practice nurses are well aware of NSF templates and lifestyle issues." (PCT B)

However more generally the PCTs' accounts indicated that awareness among health professionals of what self care really meant was variable and likely to be low:

"I'm not sure from a general practice point of view that they've really grasped the concept of self care." (PCT H)

"There's not a huge amount of awareness of self care that's badged as that." (PCT F)

"Varies a lot between practices." (PCT C)

There was recognition that PCTs needed to take action both to raise awareness of self care among health professionals and also to engage professionals in active support for self care:

"We need to promote the idea of self care to health professionals." (PCT M)
"Patchy,. . . needs more of a concerted approach." (PCT H)

A few PCTs said they had done work on this and a small number reported activity in relation to long-term conditions and EPP.

"The level of awareness is not so high but the PCT has made efforts since August to raise awareness since our PEC discussion on long term conditions." (PCT J)

"There can be tension between the medical and social models. For example our Eating Support Service because it doesn't weigh people." (PCT I)

The methods used to engage health professionals in promoting and referring people to EPP suggested considerable variation in the extent to which PCTs had reached out. In Bromley PCT, for example the two EPP course Tutors had visited all of the GP practices where they met with practice managers or attended a practice meeting. They had also met with local physiotherapists and advertised the course using a range of settings including community pharmacies and churches.

PCTs found it more difficult to assess awareness among community pharmacists although several PCTs mentioned plans to work more closely with community pharmacists in the future. One PCT, Newcastle-Under-Lyme, had developed and agreed a concordat with the Local Pharmaceutical Committee and was undertaking a patient survey through local pharmacies.

East Elmbridge and Mid Surrey PCT viewed **therapy services as a key area** for developing self care:

"The whole self care element is fundamental in therapy services."

Based on trials in other areas this PCT was piloting a future service model for physiotherapy, involving self-referral, telephone advice and triage with the intention of rolling out the service. The same PCT was also working with podiatrists to provide education sessions (patient groups targeted to date were people with Parkinson's disease and also women during the post-natal period). Advice leaflets and audio tapes had been developed to support self care.

3.4.2 Training for health professionals

Most PCTs had so far provided little training in self care for practice staff, social or health care professionals. The most commonly mentioned topic for training was weight management, reflecting current priority in PCTs to address obesity.

*"Ad hoc so far. We've run '**Training the Trainers**' for weight management." (PCT H)*

"Planning for all practice nurses to have training in an update on weight management." (PCT F)

It is unsurprising that PCTs have not engaged in training for health professionals given that strategic development of self care is currently at an early stage at local levels. Several commented that **training was a key area for the future**. One PCT saw a

priority being training and awareness raising of health professionals in self care support and non-medical options:

"They're so unaware of what they're unaware of . . . the fundamental understanding of demedicalising health." (PCT B)

Although PCTs were aware that training of health professionals was necessary, many were uncertain about what the training agenda should be:

"We have to identify their training needs to support the long term conditions agenda." (PCT H)

These data suggest that PCTs may need guidelines to develop ways for their health and social care professionals to learn about self care support.

3.4.3 Information for the public about self care

PCTs' levels of activity in information provision about self care for the public varied considerably. The most commonly mentioned activities were around information about local services and demand management type campaigns, for example, to tackle winter pressures.

Written information was the most commonly mentioned method of providing information to the public and this was often in the form of leaflets or brochures:

"We do a self care leaflet every winter." (PCT I)

East Elmbridge and mid-Surrey PCT produces a magazine, **Care Spectrum**, published four times a year. As well as being distributed to all households the magazine is available on **audio cassette tape** and large print formats. Articles on specific health topics include contact details for relevant local services, for example an item on fitness included information on activities – Walk for Health, family bike rides, GO50 (walks and cycling for people over 50), and the Fit for Life programme for people with disabilities or **recovering from illness**.

Community events were mentioned by several PCTs as an opportunity to **showcase** information about self care:

*"Displays at community events . . . our **Community Bus for diabetes**." (PCT F)*

Local radio was mentioned by PCTs I and M as a channel used regularly to provide information to the public.

The PCTs' own websites varied greatly in the amount of information they contained and whether any information was targeted at the public. Although a detailed analysis was not undertaken it was clear that some were more public-facing than others. Some websites had sections on 'Healthy Living', sometimes with links to other relevant websites, such as NHS Direct Online. A small number of PCTs mentioned plans to develop their website as a channel to provide information about self care to the public:

"We're in the early stages with the website – trying to develop it as a public health resource." (PCT J)

Most websites included at least some information about EPP but the detail was variable:

"The website is under redevelopment – it will have full information on EPP." (PCT A)

The variation in content and approach of PCT websites in relation to self care was an interesting but probably an unsurprising finding. However for the future this seems an area where discussion might be useful about what PCTs might provide locally and what NHS Direct Online provides centrally.

3.5 The Future

3.5.1 Developing new approaches

Many PCTs reported working with others in their SHA to share and develop new activities. These **SHA-wide networks** were also sometimes used to work on cross-PCT programmes or to avoid clashes of dates. Sometimes attendance at conferences or other events sparked a new initiative:

"I first heard about them (group education sessions for diabetes) from someone who had run them in Australia." (PCT C)

Several PCTs talked about how they had accessed national and international evidence base to support the design of local programmes. In Slough PCT, for example, Andrew Kimber (a joint appointee with MIND) worked with the librarian at Reading University, who conducted a literature review on the evidence base for mental health promotion. Tendring PCT had sought out researchers who had designed & evaluated school-based peer health educators. These activities had been time consuming and while there was a willingness to share this work there was not a sense of an obvious mechanism to do so.

Havering PCT was about to appoint a co-ordinator for work on physical activity with a view to developing signposting and referral to a range of activities.

Several PCTs mentioned greater involvement of community pharmacists in supporting self care in the future using the new community pharmacy contractual framework:

"Our prescribing adviser is working on the development of the role of pharmacists." (PCT M)

One PCT talked of the future development of local **district nurses** to increase their involvement in supporting self care.

"We're working with district nurses – they don't (yet) see their role as being about self care." (PCT A)

North Tees PCT is developing the role of **Health Care Assistants** to support self care, in a project that is being evaluated by the University of Teesside.

3.5.2 Planned work

The PCTs described their plans for future work to support self care:

"We're all just getting our heads around the self care agenda – looking outside doctors and nurses to provide care." (PCT B)

"We'll look at it on a condition by condition basis – heart failure, diabetes." (PCT D)

"Our main energies are being thrown into Choosing Health and implementing that." (PCT E)

All but one PCT had plans for new activities to support self care. Extending the range of settings in which support for self care might be provided was one strategy:

"Using different settings – gyms, health food shops, pharmacies." (PCT B)

*"Promote self care through the **six campaigns in the new pharmacy contract** . . . use our WIC to promote self care . . . work through A & E on minor ailments." (PCT B)*

The role of community pharmacy was mentioned by several PCTs, using both opportunities offered by the essential services component of the new contract (centrally funded) and the locally commissioned enhanced service of supporting people in relation to minor ailments:

"Minor ailment scheme in local pharmacies." (PCT B)

"Explore the use of new technology . . for example look for websites that patients could use to check inhaler technique." (PCT B)

Most of the planned work related to patient education, particularly the existing generic EPP programme:

"Hoping to work with the LTC manager on EPP." (PCT K)

Some PCTs planned to run generic EPP programmes for different client groups to extend the reach of the programme:

"I'd like to run an EPP course for carers, with a focus on carers of children." (PCT J)

"Running an EPP course working with the prison service." (PCT J)

"EPP course for carers" (PCT E)

Several PCTs mentioned plans to offer disease specific sessions. In some cases the intention was to build on the lay-led EPP model:

"Disease specific EPP development for asthma and diabetes." (PCT B)

"Want to look at disease specific sessions." (PCT M)

Another PCT was using a professional-led model for group education involving a range of different professionals and encouraging **members of patients' families** to attend. This work was well developed and was about to be piloted in a local practice:

"Planning to start group education sessions for people with diabetes and COPD, held in the practice with e.g. dietitian and foot specialist. Encouraging other family members to attend to get the whole picture. If they want, patients can have a one to one with the nurse after the session." (PCT C)

Many of the PCTs were increasing their work with local voluntary organisations and one planned to use these links to develop content for disease specific education:

"Getting patient organisations involved in developing disease specific programmes." (PCT J)

It was not clear whether the development of disease-specific sessions might be co-ordinated in some way. However it does appear that there might be a risk of duplication of work if individual PCTs identify a local need but are not aware of content and materials developed elsewhere.

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We would like to thank the PCT staff (see Appendix 2) who contributed their time to the project and shared their experiences with us.

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Appendix 1

Sample of PCTs

Random number	PCT	
67	Dartford, Gravesham & Swanley	Declined
221	South and East Dorset	
66	Darlington	
164	Newcastle under Lyme	
264	Taunton Deane	
82	East Elmbridge & mid-Surrey	
218	Slough	
235	South Sefton	
186	North Tees	
26	Bradford South & West	
119	Havering	
163	Newcastle upon Tyne	Declined
32	Bromley	
267	Tendring	
273	Uttlesford	
49	Central Suffolk	Agreed but did not participate
41	Canterbury and Coastal	
253 83	Staffordshire Moorlands East Hampshire	
4	Ashfield	

Appendix 2

Participating PCTs, respondents and their posts

PCT	Respondent	Post
South and East Dorset	Paul Harker	DPH
Darlington	Carole Harder	Director of Primary Care
	Liz Graham	Clinical Governance Manager / EPP Lead
	Catherine Bleasdale*	Workplace Health Manager
Newcastle under Lyme	Judith Parker	Health Improvement Manager / Commissioning Manager
	Jane Elliot	EPP & PALS manager
	Pat Bailes	Practice Support Manager
Taunton Deane	Tony Morkane	DPH
	Shaun Green	Prescribing Manager
	Caroline Wingrove*	Director of Primary Care
East Elmbridge & mid-Surrey	Sue Braysher	Deputy Chief Executive
	Tricia McGregor	Director of Therapies
	Claire Moonan	Specialist in Public Health
	Heather Gallagher	PALS manager / EPP lead
Slough	Rutuja Kulkarni	Health promotion programme manager
	Liz Hill	PALS/PPI Manager and EPP lead
	Andrew Kimber	Mental Health Officer
South Sefton	Cathy Warlow	Head of Health Improvement & Partnership
	Liz Johnson	Communications and PPI Manager
North Tees	Carolyn Siddle	Clinical Governance Manager / EPP lead
	Ingrid Ablett-Spence	Director of Community Nursing
Bradford South & West	Dee Kyle	Director of Public Health
	Tracy Higgins*	EPP lead
Havering	Kayode Adetugbo	Assistant DPH
	Margaret Jerwood	EPP lead
Bromley	Ian Haylock	EPP Lead
Tendring	Krishna Rhamkelawon	Assistant Director of Public Health
Uttlesford	Christine Baghurst	PALS/PPI Manager
	Glyn Pritchard	Assistant Director of Public Health

* Contact by email