Self Care Aware: Joining Up Self Care in the NHS

EVALUATION OF THE "JOINING UP SELF CARE" PROJECT IN EREWASH PRIMARY CARE TRUST

Report to the Working in Partnership Programme

October 2006

WiPP
Working in Partnership Programme

PAGB
Promoting Responsible Consumer Healthcare

REPORT CONTENTS

(excluding Annexes and separate Executive Summary document)

LIST OF ABBREVIATIONS

A&E	Accident & Emergency unit
CHAI	Commission for Healthcare Audit & Inspection (the Healthcare Commission)
CHD	Coronary Heart Disease
CHI	Commission for Healthcare Inspection (predecessor of CHAI)
DH	Department of Health
DN	District Nurse
DPP	Developing Patient Partnership
EPP	Expert Patients Programme
GMS	General Medical Services
GP	General Practitioner
HMO	Health Maintenance Organisation (USA)
HV	Health Visitor
INR	International Normalised Ratio (for blood coagulation testing)
JUSC	Joining Up Self Care
LES	Local Enhanced Service
LMC	Local Medical Committee
LPC	Local Pharmaceutical Committee
LTC	Long Term Conditions
NHS	National Health Service
OOH	Out Of Hours service
OTC	Over The Counter (non-prescription medicine)
PAGB	Proprietary Association of Great Britain
PALS	Patient Advisory & Liaison Service
PBC	Practice Based Commissioning
PCT	Primary Care Trust
PEC	Professional Executive Committee
PF	Pharmacy First (minor ailments scheme)
PR	Public Relations
PSNC	Pharmaceutical Services Negotiating Committee
SHA	Strategic Health Authority
WiPP	Working in Partnership Programme
WTE	Whole Time Equivalent

1. STUDY CONTEXT, OBJECTIVES & RATIONALE

1.1 Study Context

1.1.1 The Healthcare Context, including Self Care Policy

For the first time self care is being established as an integrated level of care in the NHS. The NHS Plan, a ten year blueprint published in 2000, calls for care to be delivered in the most appropriate setting, be that in hospital, intermediate care, primary care or, and this is the new recognition, self care. Each of these settings requires the capacity, skills and access to deliver appropriate care. Since 2000, policy regarding self care has made a meteoric rise and is documented in Annex 1.1.

While the introduction of such policies is a relatively recent occurrence, self care is not a new phenomenon. Self care has always been the first response to health but the skills have been slowly eroded over the last 50 years as the population has moved its focus to the NHS. And in this period people have become dependent not only upon the NHS but also particularly on the doctor to 'cure' all their problems. Self care as a culture has stalled. However changes and developments in society such as a rise in consumerism, a desire for choice and ease of access now create a fertile environment for self care to resurface. The time is now right to take action and instil in people the confidence once again to act independently and to adopt self care behaviour as an integral part of the way they look after their own and their families' health.

In 2002, the Department of Health mapped the self care initiatives that have been implemented over the last six years and they are presented in Annex 1.2. Many view this as a clear demonstration that they exist in their own individual domains and consulted with a number of stakeholders interested in primary care to test the hypothesis that if these programmes were considered and developed within a coherent strategy the impact on self care support would be significant.

Broadly speaking, the DH programmes can be grouped into the following categories:

- Information
- Education
- Prevention
- Management and treatment of minor conditions
- Care of people with long term conditions

Another important aspect of these initiatives is that most of them describe how the patient will move around within the NHS but do not really show how they will behave independently and appropriately outside the NHS. Prescribing by professionals other than the GP, Patient Group Directions, repeat dispensing and e-prescriptions are ways in which patients can be given fast and convenient access ultimately to treatments that are under the control of a professional. The success of 24/48-hour access to a GP has meant that people are presenting in general practice earlier than before. However fast and convenient access is not just about access to the NHS and so there is an opportunity for

self care to be offered. Further, if self care is to play a real part in building a sustainable NHS of the future there will need to be political support.

People's actions do not exist in a vacuum and cannot be ignored. The NHS needs to encompass these in the contacts that take place between patients and the NHS. While the choice agenda will be offering patients the ability to make informed choices in acute care and in primary care, the choices people make before this need to be included. The 'rights and responsibilities' agenda is a cross-departmental strategy and one where Downing Street has placed emphasis on the need for 'joined up' Government. The citizenship agenda offers the opportunity for this to take place and any work expounding the need for coherence around self care in primary care should be seen within this overarching context.

In particular, it must be noted that for a person living with a long term condition such as diabetes the average number of consultation hours within the NHS is just three hours a year, the other 8757 hours are spent on their own when the choices they make will be crucial to the care and progress of their condition. For people who do not have a long term condition or disability and might be described as 'normally healthy', the consultation hours in primary care are even less. The average number of consultations are two or three times a year and so with consultation times running at around ten minutes the interaction opportunities are around thirty minutes a year, the other 8759.5 hours are spent on their own. In this time people can develop both good and bad habits in health.

Joining up Self Care in the NHS

For the last twenty years, the Proprietary Association of Great Britain (PAGB), the national trade body representing manufacturers of over-the-counter medicines (OTC) and food supplements, has commissioned considerable research into self care and self medication[1]. PAGB has long held the view that Aneurin Bevan's vision for the NHS as a 'collective principle' does not exclude individual responsibility for health. Consequently, the very responsible behaviour pre- NHS exercised by people in taking care of their health and illness when able to do so was not intended to be replaced by the NHS as the Service was created to provide people with access to doctors on the basis of need and not ability to pay.

In comparatively recent years, there has been increasing interest from Government and others in examining what people do about their everyday illnesses, what motivates their behaviour and when and why they decide to go to the doctor. PAGB's self care studies have provided a sound base for submission to deliberations around the NHS Plan, Public

[1] For example, BMRB International (1986 and 1997), 'Everyday Healthcare – A consumer Study of Self-medication in Great Britain; McMaster Cawte Associates (1994) Report on OTC recommendation by GPs prepared for PAGB; Bradley et al. (1996) 'Attitudes and behaviour of doctors and patients with regard to over-the-counter medicines'; PAGB (1997) Qualitative Consumer Research into proposed Consumer Health Council; Reader's Digest/PAGB/NOP (2005), 'Picture of Health'.

Health White papers, NHS White papers and policies relating to the future sustainability of the NHS, Choice, Access and medicines regulations.

Having reviewed the various policies embracing self care, including the Wanless report[2] for the Treasury, PAGB was of the opinion that there was still a gap between the policy intent and the practice of implementing self care as a strategy within NHS organisations, in particular Primary Care Trusts. It was clear from the Association's research among healthcare professionals that the perceived wisdom was of self care as a practice that takes place separately from the NHS and that it is too time consuming for NHS patient consultations to include its endorsement or encouragement. It was especially the case that healthcare professionals were more interested in placing their efforts in meeting centralised targets which attract rewards than viewing the benefits that can be accrued if people are educated, informed and equipped with the tools to self care. Healthcare professionals' role in this process was not seen to be of benefit and perhaps more importantly that it was a practice that could be a barrier to their target meeting activities. Nevertheless, the underlying premise for all the policies to encompass self care is that it can result in benefits for individuals and at the same time help to manage workload in the NHS for a more effective and efficient use of valuable resources.

PAGB has worked with many stakeholders with an interest in self care since the 1980s and felt the time was right to form a steering group of many of these self care champions to create a project that would provide the evidence base to prove the benefits of self care to individuals and to the NHS.

The Association set up a Steering Group involving the stakeholders consulted who agreed that the hypothesis on the significant impact of joining up self care programmes into a coherent strategy should be tested in a PCT, which would have the benefit of offering a discrete population and a national organisational structure for the test. A list of members of the Steering Group is given in Annex 1.3.

Funding was secured from the NHS Working in Partnership Programme (WiPP) and members of the WiPP team joined the Steering Group.

Broadly, the aims of WiPP are to enable PCTs and general practices to:

- identify and analyse high-demand interventions in order to inform the development and delivery of effective services to manage those demands
- implement new ways of working, including new skill mixes, that have safely and effectively demonstrated, with patients' support, a reduction in demand for services and/or more effective use of clinicians' time
- develop the public's capacity for self care of minor ailments
- develop and deliver effective, integrated self care support services that will offer the public appropriate support, largely provided by the community and voluntary sectors, and reduce reliance on mainstream NHS services

[2] Wanless D. Securing good health for the whole population. 2004; HMSO: London

- simplify and improve the processes relating to the employment, training, development and retention of general practice managers, general practice nurses and health care assistants
- implement initiatives aimed at reducing bureaucracy.

The Joining UP Self Care project has a particular focus on two of these aims:

- ***developing the public's capacity for self care of minor ailments***
- ***developing and delivering effective, integrated self care support services.***

1.1.2 What is Self Care?

There is no brief definition of self care. The Steering Group for this project developed the following:

> 'Self care is a lifelong habit and culture. It is the action individuals take for themselves and their families to stay healthy and take care of minor and long term conditions, based on their knowledge and the information available and working in collaboration with health and social care professionals where necessary'[3].

Self care involves a spectrum of care including:

- Making healthy lifestyle choices such as physical activity and healthy eating which allow the maintenance of good health and prevention of ill-health;
- Making effective use of medicines and health care interventions;
- Self diagnosis which involves being able to make a risk assessment of symptoms, screening and assessing these, if necessary, in partnership with a healthcare professional who need not be a doctor;
- Self treatment involving responsible use of medication (OTC and prescription);
- Self monitoring involves keeping a check on signs and symptoms of flare ups and deterioration or improvement in a health condition;
- Self management which includes being able to handle the symptoms of disease either alone or in partnership with health and social care professionals or other people with the same health condition.

Self care can be described as being successful when it is a lifelong habit and culture and takes place in its own right and not as afterthought in a consultation with a healthcare professional. In order to achieve this level of behaviour a number of factors must be in place:

[3] See also Dost, A (2005). Self Care - A Real Choice, Self Care Support - A Practical Option and other Department of Health documents at **www.dh.gov.uk/selfcare** for a fuller definition and description of self care support and self care.

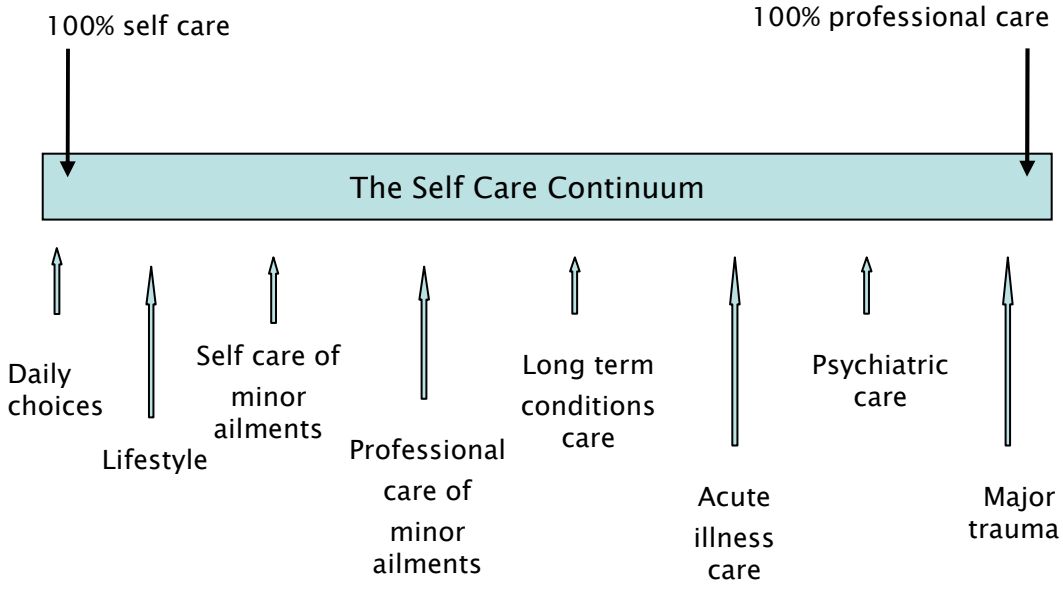
- Attitudes of individuals must be non-dependent and responsible;
- Attitudes of healthcare professionals must change to facilitate this, to build confidence and not undermine it;
- People must be capable of making informed choices which come from understanding;
- Such understanding is gained from:
    a) information and education starting with children,
    b) support from professionals providing endorsement during and after making choices'
    c) a framework or support for decision making;
- Applies to both well and ill people encompassing proactive promotion of wellness and not just crisis care of illness;
- Needs choices to be available to people.

Self care behaviour therefore leads to effective access to the next steps whether it is the NHS or other service or product and needs support in the form of information, education and advice.

The outcome of self care behaviour is wellness and empowerment. It promotes independence rather than dependence. This is perhaps the most innovative way of thinking about empowerment. In health, empowerment is often seen as the process rather than the outcome.

Steering Group member Dr Peter Smith devised the continuum of self care as a visual depiction of the spectrum of self care (Figure 1.1).

Figure 1.1: The Self Care Continuum



1.1.3 Why is self care important to the health of the nation?

Before the advent of the NHS, self-responsibility for minor ailments was the cornerstone of individual and family healthcare. Most acute conditions and childhood ailments were treated at home, often with advice from the local pharmacist.
The advent of the NHS, while leading to a general improvement in healthcare in the UK, has changed the 'culture' so that the doctor is now seen as the first, not the last, resort for minor as well as major illnesses. This behaviour diminishes the individual's rights and abilities to take care of themselves and make their own choices.

Research commissioned by PAGB and conducted by the British Market Research Bureau International[4] quantified the extent of this behaviour on the NHS:

- Minor ailments taken to the GP account for at least 96 million consultations per year.
- 39% of GP time is spent dealing with patients suffering from self-treatable minor ailments.
- Almost two-thirds of these minor ailment GP consultations result in a prescription being written. This equates to 63 million scripts, or 14% of all NHS prescriptions per year.
- Only about 5% of GP consultations for minor complaints result in an OTC medicine being recommended.

Other research commissioned by the PAGB, along with that conducted by IPPR and McKinsey for the Wanless report [5] [6] [7], shows that the decision to treat a minor ailment and how to treat it is a complex one. Factors which are relevant are the duration of the illness, previous experience of it, availability of a suitable medicine and social factors such as work and family pressures. The BMRB research shows that people change their behaviour patterns depending on the illness. People confidently self-medicate for ailments with which they are familiar but they abandon self care typically after 4-7 days.

The reasons are almost always about needing reassurance on diagnosis and confirmation that no serious disease is present. The doctor is still seen as the prime person for this reassurance even though nurses and pharmacists are capable of providing the same level of advice. In addition, while people on low incomes tend to suffer more health problems and visit the GP more often, the decision to seek GP advice for minor ailments is not

[4] BMRB International Limited (October 1997) Everyday Healthcare Study 1997: A Consumer Study of Self-medication in Great Britain
[5] Dougal-Biggs K, The HPI Research Group (May 1994) OTC Medicines and Consumers, A report of qualitative findings prepared for PAGB
[6] Kendall L (2000), Institute of Public Policy Research; 'The Future Patient'
[7] McKinsey (2001) 'Securing our Future Health: Taking a Long-Term View' cited in Wanless D Interim Report: chapter 7

significantly determined by social group (9% of symptoms suffered by social groups A,B and 10/11% among C1,C2). The key is the initial decision whether to self-medicate or to go to the doctor.

These data show that there is a need for strategies to respond to people's own beliefs, expectations and needs to help build confidence in changing help seeking behaviour. It could be argued that the one common interest in changing behaviour, which is true both for both individuals and for the NHS, is for them to be more autonomous in their actions and less dependent on the GP and the NHS.

The Wanless report[8] provided resource estimates for three different future scenarios for the health service -

- ***solid progress*** where people become more engaged in relation to there health and life expectancy rises considerably
- ***slow uptake*** where there is no change in the level of public engagement and there is some increase in life expectancy
- ***fully engaged*** where levels of public engagement in relation to their health are high, increases in life expectancy go beyond current forecasts and health status improves dramatically

Critically, the resource implication for the health service is an additional £30bn funding requirement for the *slow uptake* scenario as compared to the *fully engaged* scenario.

Wanless goes on to say that the degree to which self care becomes more important over the next 20 years will depend on the degree to which the public engages with healthcare. It is therefore closely linked to some of the other trends identified by the review associated with rising levels of knowledge, such as improved public health and increased health seeking behaviour.

Specifically, he argues for a comprehensive strategy for self care as follows:

> "*Self care is one of the best examples of how partnership between the public and the health service can work. The health service can support a pro-active public in promoting self care by, for example, helping people empower themselves with appropriate information, skills and equipment or supporting people to take a more active role in the diagnosis and treatment of a condition followed by rehabilitation and maintenance of well being. A comprehensive strategy on self care would attempt to incorporate a wide-range of approaches and models of self care, including finding ways of providing funding, information, facilities, equipment and technology to support its development."*

The Steering Group developed 'Joining Up Self Care in the NHS' as an exemplar study in the light of this.

[8] Wanless D. (2004) Securing good health for the whole population. HMSO: London

There is currently a clear shortfall in the support provided for self care. The Picker Institute submission[9] to the Joint Inquiry on the January 2006 White Paper[10] cited research showing that British patients are less likely to say they have received opportunistic advice from doctors on disease prevention and lifestyle modification than patients in the five other countries surveyed, and less likely to have been given support for self care than patients in four other countries.

The Institute argues that recognising the role that patients can play in their own care, and seeking to strengthen that role, is "fundamental to securing a more patient-centred approach to healthcare delivery, the central aim of the NHS Plan for England".

1.2 Study Objectives

The principal objective of this study was to evaluate a PCT-wide health education and promotion programme aimed at changing people's self care habits and behaviour.

The evaluation was structured around the aims of the three disease-related programme modules of the Joining Up Self Care (JUSC) programme, as follows:

1. Prevention of coronary heart disease aimed at people aged over 30 years

The aim was to increase awareness of coronary heart disease (CHD) risk factors through community focused interventions and increase the personal uptake of actions to reduce one or more of the modifiable risk factors. Wide promotion of information about CHD risk was undertaken and appropriate lifestyle interventions were encouraged.

2. Care of people with long term conditions aimed at adults with asthma.

The aim was to build on previous Expert Patients Programme activity in Erewash PCT through use of a "Staying Well with Asthma" programme aimed at improving outcomes through self care, and building participants' confidence in taking care of their own asthma and that of any other family members.

3. Treatment of minor ailments aimed at mothers and young families.

The aim was to evaluate an integrated intervention to increase self care behaviour for the care of minor conditions; to assess the effect of the intervention on mothers and their families; to focus on support for mothers and children, with seasonal activity to promote and add value to existing initiatives to increase

[9] Picker Institute evidence to the Joint Inquiry into the White Paper Our Health, Our Care, Our Say by the All Party Parliamentary Group on Primary Care, Public Health & Social Care; June 2006 (unpublished)
[10] Department of Health (2006). Our Health, Our Care, Our Say – a new direction for community services; TSO: London

mothers' confidence to undertake self care and to assess the effects on use of health services for minor ailments.

The aim included the expansion and promotion of the PCT's pharmacy minor ailments scheme ("Pharmacy First") with a particular focus on mothers for the management of minor conditions in their children aged 3 months to 12 years.

The secondary objective was to evaluate the impact of the JUSC programme on health professional attitudes and on the PCT itself.

The choice of the three modules summarised above reflects the need to examine the impact of the approach in relation to disease prevention (coronary heart disease), care of people with long term conditions (asthma) and the treatment of minor ailments in line with existing PCT strategies and targets.

1.3 Study Rationale

Self care has previously been identified as a means of both improving health outcomes and improving access to appropriate care (as indicated in section 1.1.3 above). The Wanless report also confirmed that the UK has fewer nurses and doctors per head of population than most other European countries. There is clear recognition within the NHS that equipping the public with knowledge and skills to increase self care of health is likely to produce benefits for both the public and for the NHS. The General Medical Services contract has explicitly stated an intention to develop and test new ways of working in relation to managing minor ailments and increased care of people with long term conditions.

A number of existing Department of Health and NHS initiatives involve and relate to supporting self care, but recent research shows that these have not so far been 'joined-up' in a whole systems approach at local level[11,12]. This project therefore evaluated the benefits of the first PCT-wide integrated, coherent programme of supported self care.

It was not the intention of the study to invent anything new but rather to build on existing initiatives and programmes supporting self care. The PCT delivered three service modules relating to disease prevention (community-based CHD prevention), care of people with long term conditions (Expert Patients and Asthma UK Programme in asthma) and the management of minor ailments.

While the JUSC Steering Group undertook to fund the evaluation of the project, the participating PCT had to undertake the cost of operationalising the interventions which was estimated to be £94,000. Erewash PCT was able to give this undertaking. The

[11] Blenkinsopp A and Ayesha Dost. (2004) Self care support: a scoping study across the health and social care whole system. Department of Health.
[12] Blenkinsopp A. (2003) Minor ailments management and self-care: a scoping study to describe the range of models. Keele University, Department of Medicines Management.
http://www.keele.ac.uk/depts/mm/Publications/Reports.htm

Steering Group was awarded a fund of £300,000 for the evaluation from the Working in Partnership Programme, which was established under the new GMS contract in accordance with chapter 6.46–6.48 on workload management entitled 'Working in Partnership' (see Annex 1.4).

Prevention of CHD module

While general practice-based activities to influence behaviours associated with risks for coronary heart disease are well-established, less attention has been paid to community-based individual risk assessment and promotion. The latter approach has the potential to reach members of the public who do not regard themselves as 'at risk' and may not take up general practice-based initiatives. The evaluation assesses any changes in lifestyle behaviour as a result of this promotion.

Asthma module

The Expert Patients Programme (EPP) is now well-established in the NHS. There is good evidence that the type of courses being run in EPP lead to people feeling more in control of their condition, resulting in reduced use of health services and lower treatment costs.[13,14,15,1617]

The EPP has shown that people with long term conditions can also be empowered to take more responsibility for self care. The JUSC objectives initially included the intention to develop an 'expert parents programme' for the parents and carers of children with asthma and Erewash PCT was particularly enthusiastic about this. There would have been two components to this approach; a disease specific EPP and empowerment of parents and carers to give them the confidence, in turn, to instil confidence in children. However, a year into the study design, the EPP was not yet at a stage where the Department of Health could provide permission for the intended programme to be developed.

It was therefore necessary to design an alternative. The development of asthma-specific self care skills training session, and promotion of these with other self care support initiatives, had not so far been evaluated and the Steering Group and PCT decided to proceed with an EPP for adults with asthma as this evaluation would fill the gap. The programme was promoted under the heading of "Staying Well with Asthma". The

[13] Barlow JH, Wright CC, Sheasby JE, Turner AP, Hainsworth JM (2002) Self-management approaches for people with chronic conditions: A review. *Patient Education & Counseling*. 48, 177-187.
[14] Barlow JH, Hearnshaw H & Sturt J (2002) Self-management interventions for people with chronic conditions in primary care: Examples from arthritis, asthma and diabetes. *Health Education Journal*. 61, (4), 365-378.
[15] Bodenheimer T, Lorig K, Holman H, Grumbach K. (2002) Patient self-management of chronic disease in primary care. *Journal of the American Medical Associatio*;288(19):2469-2475.
[16] Lorig K, Holman H. (2003) Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med*: 26(1):1-7
[17] National Expert Patients Programme Internal Monitoring Report (2005). Department of Health, England.

change from the original programme was delayed by several months and thus the follow-up period was limited.

Minor Ailments module

A number of PCTs have introduced community pharmacy-based schemes to support the transfer of minor ailments management away from GP consultations so that doctors can spend more time dealing with more serious conditions. A review of previous schemes showed that they are acceptable to, and well used by, the public[18]. However, only one scheme has measured the impact on GP workload[19] and none have investigated the effect on people's self-confidence in dealing with minor ailments or the likelihood of future use of health services for this purpose. The JUSC evaluation aims to fill these gaps.

However, there is evidence from research into a pilot minor ailments scheme in Scotland which went nationwide in 2006[20,21]. The Scottish research of the pilot phase indicates that uptake is slow. After 12 months 4% of patients registered with GPs in Area 1 had registered with the scheme and 23.3% in Area 2. These figures increased to 5.6% in Area 1 and 26.9% in Area 2 at 18 months. The scheme was mainly used by those aged under 16, (59% of consultations). Those with income-related exemptions accounted for 19% of consultations. Only 13% were aged 60 and above.

Head lice was the most frequently presented condition at community pharmacies followed by pain and cough. Apart from these conditions there were no other identifiable shifts of consultations away from GPs to community pharmacies. Community pharmacists were generally favourable towards the scheme and GPs were broadly supportive though they noticed little impact on their overall workload.

The implications of this for the JUSC project are that while the full effects of the scheme are unlikely to be reached within the study timeframe, the JUSC policy of targeting mothers of young children reflects the success of this previous scheme. Data on numbers of pharmacy consultations will be available during JUSC, primary care workload is unlikely to be noticeably affected during the timeframe of the JUSC study.

Another aspect of minor ailments care is the confidence people generally have in their own ability to deal with coughs, colds, headaches etc. A community wide information

[18] Blenkinsopp A, Noyce P. (2002) Minor illness management in primary care: a review of community pharmacy NHS schemes. Keele University, Department of Medicines Management. http://www.keele.ac.uk/depts/mm/Publications/Reports.htm

[19] Hassell K, Whittington Z, Cantrill J, Bates F, Rogers A, Noyce P. (2001) Managing demand: transfer of management of self limiting conditions from general practice to community pharmacies. *BMJ.* July 21; 323(7305): 146-147.

[20] Schafheutle E, Noyce P, Sheehy C, Jones L. (2003) Direct Supply of Medicines in Scotland: Evaluation of a Pilot Scheme. Health & Community Care Research Programme, Scottish Executive Social Research, Research Findings No. 29.

[21] Sheehy C, Jones L. (2003) Direct Supply of Medicines in Scotland: Extended Monitoring of a Pilot Scheme. Health & Community Care Research Programme, Scottish Executive Social Research. Research Findings No. 30.

campaign was devised to provide people with accessible information on how to recognise and deal with these symptoms themselves and help with knowing when to seek advice from a pharmacist, nurse or doctor. The information was provided by the charity DPP (Developing Patient Partnerships) in the form of booklets and leaflets.

Healthcare Professionals

As many as 300,000 GP consultations a day are for minor ailments that could have been dealt with by the individual through self care and self-medication[22] and patients with long term conditions are increasingly interested in self-managing many of the symptoms of their conditions as well as having coping strategies for their lives on a day-to-day basis. For this reason, the study included a significant proportion of effort in the engagement of all healthcare professionals in becoming actively involved in supporting the JUSC programme.

In addition, a baseline study of activity and development in self care support in PCTs and local areas[23] discovered that in 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.

A confounding factor during the set up and implementation of the project was firstly, the implementation of the nGMS contract 2004 and the pharmacy contract in 2005. This significantly slowed the adoption of the implementation of the study interventions by these two health professionals as their priorities were set on the implementation of the new requirements of their respective contracts which needed discussions with the PCT.

Nevertheless, training on self care aware consultations was devised to address the engagement of healthcare professionals.

[22] Whittington Z, Hassell K, Cantrill J, Noyce P. (2001) Care at the Chemist: A Question of Access. Report to the Community Pharmacy Research Consortium.
[23] Department of Health (2005). Self Care Support: Baseline study of activity and development in self care support in PCTs and local areas (see www.dh.gov.uk/selfcare)

2. STUDY DESIGN

2.1 Overall Study Design

This was a longitudinal study of patient/public and health professional attitudes and behaviours, comparing baseline measures during the period February-December 2005 with measures 5-12 months later (February-May 2006). The study Steering Group was closely involved in developing the study design and its subsequent implementation.

The underlying hypothesis was that patient/public respondents to the PCT's self care activities (summarised in Section 3) would take more responsibility for their own health by addressing some of the modifiable risk factors for CHD, taking care of asthma with more confidence, and using community pharmacists and NHS Direct for advice and treatment of minor ailments.

The Steering Group originally designed an action research study and were consequently of the opinion that control groups would not be appropriate. Comparisons pre- and post-intervention would provide sufficient data. In discussion following the WiPP funding decision, it was agreed that controls would be included from the same PCT as the intervention groups. (Controls recruited from a different PCT would incur problems of normalisation for PCT-specific factors) However, the control groups in Erewash could obviously not be isolated from the general self care promotional activity so they do not represent a "pure" comparison.

The evaluation method employed both quantitative techniques in the form of postal survey questionnaires and qualitative techniques including focus groups and (for health professionals) individual interviews. Control groups were recruited at baseline for the Asthma and Minor Ailments modules, and at follow-up (via a community-wide survey) for the CHD module.

The reasons for not recruiting controls at baseline for the CHD module can be summarised as follows:

- The CHD module was aimed at disease prevention in the general adult population, and therefore differed from the other interventions.
- Collecting data on behavioural measures at baseline risked biasing the sample through increased levels of awareness.

Follow-up amongst a wide community sample was therefore considered more appropriate for the CHD module than identification of a control group at baseline. This community-wide survey also provided an opportunity to assess general awareness of the self care promotional activity within the PCT.

In addition, the attitudes of health professionals (specifically GPs, pharmacists, practice and district nurses, school and nursery nurses, health visitors and PCT staff) towards the JUSC programme, its implementation and its sustainability were assessed qualitatively.

Pilots of the postal survey questionnaires were undertaken to ensure their understandability and feasibility.

The full evaluation study protocol is given in Annex 2.1.

2.2 Outcome Measures

The primary outcomes comprised uptake of self care measures and intentions for future behaviour, specifically:

> ***Prevention of CHD:*** uptake of diet change, exercise, smoking cessation and reduced alcohol consumption, plus consultation rates with health professionals regarding heart health.
>
> ***Asthma:*** participation levels in the "Staying Well with Asthma" programme, participants' attitudes towards taking care of their asthma, attitudes towards taking care of asthma of any other family members, medicines usage, and GP consultation rates for asthma.
>
> ***Minor Ailments:*** participation levels in "Pharmacy First", increased use of pharmacies and NHS Direct for advice, reduced rates of GP consultations for children's minor ailments, prescriptions for specific minor ailments and prescribing indicators including head lice treatments and antibiotic prescribing, plus awareness levels of self care options and likely future actions by mothers.

The secondary outcomes were:

> Professional attitudes towards CHD prevention and the effective provision of lifestyle advice.
>
> Concordance between "Staying Well with Asthma" participants and healthcare professionals on asthma management.
>
> Professional attitudes towards the management of minor ailments.
>
> Awareness of the self care programme and use of sources of healthcare advice amongst the general population of the PCT.
>
> Operational implications for the PCT of sustaining the self care support programme overall.

2.3 PCT Selection & Profile of Erewash PCT

In October 2003 the Dept of Health provided an initial list of 23 possible PCTs which might be interested in collaborating on the JUSC project. All these PCTs were contacted

by the PAGB and 16 of them requested a JUSC information pack. This pack, sent in January 2004, included a project summary covering its rationale and objectives, the three proposed modules of activity on CHD prevention, asthma management and minor ailments and what the PCT would be expected to do as part of the project.

A cost breakdown was also provided in the information pack. This indicated that the PCT would be expected to contribute approximately £94,000 in the form of reimbursement to health professionals, OTC medicines as part of the Minor Ailments module, risk assessment material related to the CHD module, expenses for meetings, and a 0.75 FTE project facilitator.

Responses from 15 PCTs were considered and four were the invited to the PAGB office for discussion and a panel of JUSC Steering Group members, including the Chairman.

The criteria for selection of the participating PCT were:

Essential characteristics:

- To have a PCT champion for supporting self care and be keen to participate,
- To have management and clinician commitment and local champions,
- To have project management capacity and commitment to data collection,
- To have a representative sample of patient population and demographics around age, socio-economic status, ethnicity and employment.
- Be prepared to fund the implementation of the self care support programme as part of its cost of local delivery of quality of care as required by the new GMS contract.

Desirable characteristics:

- Existing or planned pharmacy minor ailment scheme
- Experience of running Expert Patients Programme sessions
- Experience of working in local strategic partnerships
- Existing or planned post of Director of Public Health

In promoting the applications for the study the following benefits of participating in the study were communicated:

- helping to deliver targets
- meeting advanced access criteria
- enabling the then CHI (CHAI) evaluation criteria to be met
- helping in establishing local quality criteria as required under the new GMS Contract
- improving health outcomes
- amassing evidence of the practical application of a self care support programme in the specified areas, which can be applied to many others and address the management of demand

- establishing a way of working which creates capacity in general practice and makes effective use of the skill mix thereby demonstrating workforce development
- establishing means of working in strategic partnerships.

The application and interview process produced the successful candidate in Erewash PCT. The PCT satisfied both essential and desirable characteristics for the study as the following list of existing activities showed:

- Expert Patients Programme – three groups started, two already completed programme
- Workshops for people with diabetes
- Keep Well in Winter roadshows – multi-agency linked to flu vaccination campaign
- Expert patients managing own anticoagulation care with own near patient testing kits – 25 to date
- Sure Start – pharmacy minor ailments pilot
- Partnerships with voluntary sector including:
  - CHD prevention/Healthy Eating – working with children on allotments
  - Exercise/sports opportunities for older and younger people in areas of deprivation
- Innovative pilot by School Nurses to give NRT to 13-16 year olds to help them quit smoking
- "Your Life" magazine (DH/Dr Foster) targeting young women with self care and family-care messages
- Medicines Management Collaborative
- DH funded Active Life site within the PCT area working with older people to improve health literacy
- Discovery interview project – interviewing patients carers/users to lead to user/carer inspired service changes
- Links to Asda for healthy living for their staff

Erewash PCT stated that the concept of self care was already recognised and supported within the PCT and the then Chief Executive wrote that "there is real excitement from those involved in developing this proposal around the prospect of putting the spotlight on this vital but previously neglected area." In the application letter and during the interview the PCT acknowledged the benefits that they felt they would accrue in taking part in the study:

- providing a focus on self care and enabling strands of work already underway to be coordinated
- providing the in depth evaluation to the project which is so often lacking in NHS pilot work
- taking self care to the next "level" in terms of developing Expert Parents and from this provide the springboard to Expert Carers which is desperately needed

- ensuring that healthcare resources are appropriately both used and allocated – right care in the right place at the right time for patients
- assisting primary care to maintain the access targets already achieved and enable the achievement of the forthcoming 100% target
- providing the vital building block of self care as the PCT develops the HMO model in Erewash involving more employers to become involved in maintaining a "well" workforce

Erewash PCT was also considered to be approximately in line with the average for England on several demographic and health service measures (Table 2.1).

Table 2.1: Summary Profile of Erewash PCT

	Erewash PCT	England Average
Total population[24]	109,979	164,617 per PCT[25]
% Unemployed[1]	3.3%	3.4%
% Retired[1]	14.1%	13.6%
% Permanently sick or disabled[1]	5.2%	5.5%
% One person households[1]	27.7%	30.0% (Eng & Wales)
% Households with dependent children[1]	30.0%	29.5% (Eng & Wales)
Owner occupied households[1]	78.3%	68.9% (Eng & Wales)
Number of GPs per 100,000 population[1]	52.0	53.2[26]
Number of pharmacies per 100,000 population[27]	18.7	19.5

Erewash has two main areas of population, Ilkeston in the north and Long Eaton in the south, each with a population of approximately 37,000. In 2004, 18% of the PCT's population were aged 14 or under, and 16% were aged 65 or over. This age structure has remained relatively stable, although there has been a growth in the older population in line with national trends. Ethnicity in the PCT is predominantly white.

There are 14 GP practices in the PCT. At the start of the JUSC period there were 18 community pharmacies, and this has subsequently grown to 20 as a result of changes in the control of entry regulations.

Ilkeston Hospital was England's first community hospital to be built on a greenfield site and opened in 1987. It has a Minor Injuries Unit, an Outpatient Department and a Diagnostic and Treatment Centre, which opened in 2003. Medical cover for inpatients is provided by local GPs and visiting consultants. The Minor Injuries Unit became nurse-led in 2002, with local GPs undertaking specialist follow-up clinics.

[24] Erewash Public Health Directorate based on 2001 Census
[25] www.dh.gov.uk/PublicationsAndStatistics/Statistics/StatisticalWorkAreas/StatisticalHealthCare
[26] Department of Health (2002). Shifting the Balance of Power; HMSO: London
[27] Department of Health (2002). General Pharmaceutical Services in England & Wales, Statistical Bulletin, 2000-2001

Long Eaton Health Centre recently enjoyed a major redevelopment as a "one stop primary care centre" and re-opened in 2006.

At the time of writing, the PCT is undergoing structural change in preparation for its merger with five other PCTs in Derbyshire as part of the NHS reform programme.

2.4 Study Management & Funding

The study was overseen by a Steering Group, membership of which is given in Appendix 2.1. Project management for implementation of the JUSC programme itself was undertaken by Erewash PCT. Project management for the evaluation including all data analysis was undertaken by PMSI Healthcare, a specialist health policy and research consultancy (www.pmsi-healthcare.com).

Funding for the evaluation was provided by the Department of Health WiPP initiative, but resources for the implementation of self care activities were also provided by the PCT.

Ethical approval for the evaluation was obtained from Derbyshire Research Ethics Committee.

2.5 Challenges & Changes

There were a number of challenges and changes during the implementation of the JUSC project.

These related firstly to staffing, management and resources at the PCT:

- The PCT's Communications Officer went on maternity leave from January to July 2005. This covered the important start-up phase of the JUSC project; a local PR Agency was employed from February to July but this inevitably led to some discontinuity
- The Self Care Project Manager (0.6 WTE, although initially not all this time was spent on JUSC) went on maternity leave from April to November 2005 Her role was covered by the Primary Care Project & Development Manager
- In July 2005 the PCT's Director of Strategic Development was given overall responsibility for the JUSC project, but she resigned from her position in September 2005
- In September 2005 the PCT's Chief Executive resigned. Her role was taken over by the Assistant Chief Executive, who then also resigned within two months. In January 2006 the PCT's Associate Director of Service Development took over responsibility for JUSC
- It became clear that more resource was required at the PCT in order to implement the evaluation of JUSC (eg mailing and recording of

questionnaires, since the JUSC project management team had to remain blind to patient identities). It was therefore agreed that financial support should be provided to enable a 0.6 WTE admin post to support the Self Care Project Manager.

In addition, there were a number of challenges resulting from the new GP and pharmacy contracts which were introduced during the period of the JUSC project. This meant the attention of PCT management and some health professionals was understandably distracted from the specifics of the JUSC project and the role of self care (although there are parts of both new contracts that relate to self care). In particular, engagement of GPs during a period when there was intense focus on the new QOF targets proved difficult.

The second area of change was in the nature of the interventions. The most significant of these changes were as follows:

CHD

The initial study protocol envisaged use of a computer risk assessment programme, CardioRisk®, to be located in community pharmacies. However, this did not prove feasible and the risk assessment tool was changed to a leaflet with a "wheel" for individuals to assess their CHD risk based on age, gender, smoking status, family history and weight. The text on the leaflet encouraged users to contact their local pharmacy or to call a 0800 number to obtain a lifestyle advice pack.

These leaflets were distributed widely within the PCT from February 2005 but requests for the lifestyle packs were lower than desired. In May 2005 it was therefore decided to work with local employers to distribute baseline questionnaires direct to their employees, with all respondents being sent a lifestyle pack and also being entered into a free prize draw. This considerably boosted the response rate for the CHD intervention group.

Asthma

The initial study protocol envisaged recruitment of parents or carers of children with asthma to the intervention group. However, following the DH decision not to proceed with the course for parents and carers, it was necessary to consult with the Board of Erewash PCT to find a way forward. The PCT had been particularly keen to run a programme for parents and carers but were ultimately convinced that there was merit in providing an EPP programme for patients with a specific disease. The protocol was consequently changed to focus on adults with asthma. The Steering Group decided to provide the six week generic EPP course with a seventh week session on asthma. It was possible to recover some of the lost time because DH and Asthma UK had previously jointly developed and piloted such a session and gave permission for its use in JUSC.

Recruitment to the EPP proved difficult from the early stages of the study. The JUSC study tested an invitation letter from the GP to patients on the practice asthma register to attend "Staying Well with Asthma". However, many of those patients expressing interest in response to the GPs' letter were unable to commit to the seven week course at the times proposed. It was therefore decided to run individual half day asthma taster sessions in September and November 2005. These events served the purpose of providing a "taster" session on the EPP.

One effect of this change was that two different interventions were employed in the asthma module, with some overlap since some EPP participants also attended one of the half day sessions. Where relevant, data have been reported for the EPP subgroup separately from those who only attended the half day session, although the respondent numbers in each subgroup are obviously smaller than for the whole intervention group.

Minor Ailments

The Pharmacy First minor ailments scheme was already in place in the Ilkeston area of the PCT before the start of the JUSC project. This area was therefore targeted for recruitment of the intervention group, with the control group recruited from the other area, Long Eaton.

However, from October 2005 Pharmacy First started to be rolled out in Long Eaton. As a result of this, some control group participants were switched to the intervention group if they registered in Long Eaton. This boosted intervention group numbers but it led to a wide variation in the length of time during which respondents had been registered with Pharmacy First.

Alongside this, four seasonal minor ailment press campaigns with accompanying leaflets as well as two booklets aimed at adults looking after their minor ailments and caring for children with minor ailments were launched and distributed throughout the PCT.

3. EREWASH PCT ACTIVITIES IN SUPPORTING SELF CARE

3.1 Overview

Erewash PCT's enthusiasm seen during the interview process did not wane throughout the duration of the Project, despite a number of challenging moments. This was mainly because the Project fitted with its strategic direction. Erewash PCT had the foresight to recognise the benefits and potentials for self care long before other PCTs realised its value. Self care was seen by the PCT as essential for meeting Government targets and helping with the increasing demand in primary care.

To underpin the PCT's own initiatives the Government's policies on self care, including the NHS Plan, the Public Health White Paper "Choosing Health" and "Supporting people with long term conditions to self care' provided the national context. The socio-economic context was provided by the Wanless reports for the Treasury, which focussed on self care as an essential component of the NHS's sustainability. Over the course of the project national policies continued to be published.

Before JUSC, Erewash PCT had already begun to explore various self care activities and had started to make progress with these initiatives. Examples of what was happening in Erewash PCT before JUSC were included in their application form (see annex 3.0 for the full application form and reasons behind Erewash PCT's decision to apply to be the exemplar PCT).

The activities included:

- Expert Patients Programme – three groups started, two already completed programme
- Workshops for people with diabetes
- "Keep Well in Winter" roadshows – multi-agency linked to flu vaccination campaign
- Patients managing their own anticoagulation care with near-patient testing kits
- Sure Start – pharmacy minor ailments pilot
- Partnerships with voluntary sector including:
  - CHD prevention/Healthy Eating – working with children on allotments
  - Exercise/sports opportunities for older and younger people in areas of deprivation
- Innovative pilot by School Nurses to give nicotine replacement therapy to 13-16 year olds to help them quit smoking
- "Your Life" magazine (DH/Dr Foster) targeting young women with self care and family-care messages
- Medicines Management Collaborative
- DH funded "Active Life" site within PCT working with older people
- "Discovery" interview project – interviewing patients and carers to lead to user/carer inspired service changes
- Links to Asda for healthy living for their staff

Erewash PCT were chosen to be the exemplar PCT because they had already proved their support for self care, and they felt that JUSC provided an ideal opportunity to build on existing self care initiatives. Having services rigorously evaluated was also very exciting for the PCT and was likely to result in a way of working more efficiently in the future. The PCT was looking forward to having a wealth of valuable expertise and support in the form of the multi-disciplinary JUSC Steering Group.

Whilst the evaluation of the Project was funded by the Working in Partnership Programme, implementation of JUSC was very much the responsibility of the PCT. Costs involved in implementing a comprehensive programme for the three disease-specific self care modules included the production of materials, running events and courses, holding campaigns and press launches, occasionally employing expert staff, purchasing promotional tools and of course, the personnel costs that are necessary to administer a successful programme such as JUSC. (See annex 3.1 for cost details).

3.2 PCT Organisational Structure

The first task undertaken by Erewash PCT was to identify the team of appropriate people within the PCT to ensure the project was cross departmental. It was intended that this team should work closely with the PCT Self Care Programme Manager (0.6 WTE) who would be responsible for pulling together the relevant elements of JUSC. The premise of the project was about "joining up self care in the NHS" so cross departmental communications within the PCT were recognised as important. The self care team consisted of the Chief Executive, Director for Primary Care, Head of the Prescribing Team, Public Involvement Manager, Associate Director of Health Improvements and Communications Officer plus the PCT Self Care Programme Manager who was tasked with the job of bringing it all together (see annex 3.2 for list of PCT employees involved in the Project),.

However, this was a "virtual" team. The PCT Chief Executive was the project champion but had to become more involved than was initially envisaged. By early summer 2005 it therefore became clear that an operational Board level Director needed to be given specific responsibility for not only the JUSC project but also the PCT's overall strategy for self care. This was particularly needed to support the PCT Self Care Programme Manager gaining sufficient attention for the project and in joining up self care within the PCT. The responsibility was given to the Director of Strategic Development but she left the PCT in September 2005.

It also became clear that additional administrative support was required for the Self Care Programme Manager to implement all the requirements of the JUSC project and the associated evaluation research. A part time admin post was therefore created to facilitate this support.

Work on the process of a self care strategy began by the PCT Self Care Programme Manager in March 2005. However, a series of personnel changes made it difficult to complete the document. Discussions are currently underway to develop a Derbyshire-

wide self care strategy and a re-drafted document is being produced (see annex 3.3 for the strategy development process).

3.3 Joined Up Working

During the early stages of the Project, the PCT Self Care Programme Manager established important contacts with numerous community agencies and individuals within Erewash advising them about the self care project and exploring the various connections that could be made to progress JUSC (see annex 3.4 for local partnership agencies). Communications with new and old contacts were made constantly throughout the duration of the Project with extra effort made with local healthcare professionals since their co-operation in making self care happen was imperative.

A list of these local contacts was put together and played a significant role in the dissemination of intervention materials for each module. (See annex 3.5 for the distribution list of local contacts).

Developing the intervention material also meant involving local and national experts. Contributions were made by a wide array of individuals and organisations during various stages in developing the material. Expert sources including the British Heart Foundation and the Food Standards Agency were used for specialist information within the CHD module, and Asthma UK helped considerably with details on the asthma module throughout the duration of the project. Ayesha Dost, Principal Analyst and Policy Adviser in the DH Strategy Directorate and also Self Care Co-lead at the DH and who has been involved in the designing, setting up and roll out of the Expert Patients Programme offered a great deal of helpful advice and contact information during the vital early stages of the asthma module.

For the minor ailment module advice and background data were provided by Professor Alison Blenkinsopp from Keele University who had just completed a comprehensive investigation into minor ailments management and self care for the DH and had written the pharmacy scheme toolkit with the National Prescribing Centre. The charity organisation Developing Patient Partnership (DPP) which produces user-tested health information also assisted by providing self care material for the minor ailments module.

3.4 Raising Awareness of JUSC

Promotion is absolutely crucial for any programme with the objective of changing attitudes and behaviour. Raising the profile of self care within Erewash meant a robust and comprehensive communications programme was essential if any kind of impact was to be made. A local PR Agency, PR Principles was employed from February to July 2005 to coordinate media publicity for the minor ailments seasonal campaigns in particular, while the PCT's Communications Manager was on maternity leave.

For the promotional programme particular attention was paid to special health days such as "No Smoking Day", "World Asthma Day" etc with small seasonal campaigns planned to help promote one strand of the minor ailments module. There was an excellent launch of the project on 14 February 2005, with an emphasis on CHD coinciding with a "Heart" theme for Valentines Day. The local Mayor and his wife attended a photo shoot at the local leisure centre and the PCT Chief Executive, Paula Clark gave local radio and television interviews. A lot of local press attention was also generated.

Although the budget was rather limited, the PR campaigns produced a fair amount of local publicity, but this could not be sustained for the duration of the project and communications were moved "in-house" in August 2005.

Part way through the project, the PCT Self care Programme Manager managed to secure a monthly editorial with the local newspaper Trader Group and provided articles on how to recognise and treat minor ailments. Local partnership organisations also helped in spreading the word with ongoing multi-agency health promotion events taking place throughout the timeframe of the Project. (Annex 3.6 has the full list of publicity generated throughout the months of the Project).

3.5 Coronary Heart Disease

Initially a two-step wheel device was developed called the "Erewash Heart to Heart Assessment", which was a self assessment card used to identify the reader's risk of contracting coronary heart disease based on current lifestyle behaviour as well as family history. Risk is identified based on a traffic light system of colours, higher risk being red. The reader was then advised to telephone for a lifestyle pack or collect one from community pharmacists. Information contained within the packs consisted of practical advice on making healthy lifestyle changes and information on local services and activities promoting heart health.

These wheels were colourful, eye-catching and easy to use. The prototype was piloted with local people and resulted in some changes. Further consultation was necessary however and the wheel and packs were sent out widely to be evaluated by local consultant cardiologists, GPs, a dietician, the PCT reader's panel and an exercise tutor.

Wheels and lifestyle packs were distributed to community pharmacists with a window display promoting JUSC. Between February and May 2005 wheels were continually promoted with 10,000 eventually being distributed throughout the Erewash area (see annex 3.7 for list of CHD campaigns and CHD materials).

Uptake of wheels and information packs were constantly monitored with updates reported at each Steering Group meeting. It quickly became apparent that the two-step intervention was not working. Large numbers of wheels had been distributed with a limited number of packs being requested. As part of the evaluation it was essential that more lifestyle packs were distributed since evaluation questionnaires were included in the packs. The decision was therefore taken to change to a simpler one-step intervention.

This did not mean scrapping the intervention material completely. The packs were made into lifestyle information booklets 'How Healthy is your Heart?' which were no longer colour coded red, green or amber. And questionnaires were distributed with the booklets to continue the evaluation.

Distribution at this stage was mainly through employers in Erewash with 13 organisations participating. These companies distributed the healthy heart booklets (and questionnaires) to employees as well as the 'Better Health at Home and at Work' booklets which is part of the minor ailments module. There was an extra incentive to return questionnaires since respondents would be entered into a prize draw. To add an extra strength to the promotion it tied-in with British Heart Week (see annex 3.8 for employers that were involved).

Further promotional events took place throughout Erewash including media campaigns with posters placed in most of the community settings throughout Erewash. (See annex 3.9 for the list of non-JUSC CHD campaigns). In January 2006 a targeted "stop smoking" mailing was issued to baseline respondents who had said they were smokers.

3.6 Care of People with Long Term Conditions – "Staying Well with Asthma"

Since the originally planned "Expert Parents Programme" could not go ahead it was necessary to design an alternative.

Initially the revised intervention for the asthma module was ten seven week generic Expert Patients Programme courses with the final session of the course (on week seven) concentrating on how to self care for asthma. (Please see annex 3.10 for the asthma specific programme).

The Regional EPP Co-ordinator was instrumental in driving the promotion, recruitment and delivery of the courses. The Co-ordinator was supported by the PCT Patient and Public Involvement Manager who was also the EPP Lead for the PCT. Their involvement was particularly important since there were some problems in recruiting people for the intervention courses.

General Practices were also an important factor in making this element of the project happen. Work began in April 2005 by identifying people with asthma through general practices. Those identified (1771 people) were invited to participate in the study either as part of the control group or the intervention group. The intervention group agreed to attend a seven week Expert Patients Programme course for people with asthma. To help encourage participation in the course the final 550 letters included a personal statement from an EPP volunteer tutor with asthma explaining how the EPP course had helped him change his life around.

Promotion about the courses was widespread with *Staying Well with Asthma* flyers, posters and leaflets distributed throughout Erewash.

As well as recruiting for people with asthma to attend courses it was also necessary to recruit trained asthma nurses to assist in the courses. A training event was held in April 2005 attended by nine local nurses and five EPP trainers; the event was run by the national EPP trainer.

The first course started in May 2005 but was cancelled due to lack of attendance. Another attempt was made to recruit more people and letters and leaflets were sent to asthma nurses at general practices, community pharmacists and the PALS service to encourage course promotion. A further push on promotion provided a few more participants but not enough to continue with a seven week course.

Feedback from patients that received the invitation letter but did not want to join the intervention group was that the seven week course was too long and so two half day events were planned instead with a taster programme based on materials written by Asthma UK but incorporating some exercises from the EPP course which encouraged interaction with attendees. The events were facilitated by two EPP tutors (one of whom had asthma) and a respiratory nurse. A local community pharmacist was present to answer specific questions about medicines (see annex 3.11 for event details).

Once again another promotional campaign took place to recruit people with asthma including advertisements in the local newspapers. Community pharmacists, practice nurses and practice managers were also encouraged to promote the events.

Two successful half day events were held in September 2005 with 76 people attending in total. A further evening event was held in November 2005 which was not as well attended with just 12 delegates. (See annex 3.12 for the evaluation on courses and feedback on the reasons behind people not attending the 7 week course).

The half day events provided people with the information they needed to make a decision on signing up for two full EPP courses which took place in September and October 2005. Without the 'taster' sessions at the half day events people were reluctant to devote seven weeks of their time.

A reunion for the EPP attendees was held in April 2006 with positive feedback about the courses. Some participants said it was life changing, expressing the wish to set up a self care support group for people with asthma.

3.7 Minor Ailments Module

The minor ailments module of the JUSC Project was made up of three elements:

1. minor ailment pharmacy scheme (Pharmacy First)
2. health information campaigns
3. self care aware training for healthcare professional (see chapter 8 for details)

Pharmacy minor ailment scheme

Work on the Pharmacy First minor ailments service was underway before Erewash PCT was chosen as the exemplar PCT which saved a great deal of time. The scheme went live in the north of Erewash (Ilkeston) in July 2004. The service was designed to allow for convenient access to advice and treatments, giving people the choice of visiting their community pharmacist for a consultation and receiving medicines for a wide range of minor conditions. Patients received guidance and advice on how to take care of minor ailments for themselves and their children. It was felt that this would encourage self care behaviour since those who would otherwise access the GP or A&E for a free NHS prescription could obtain the same medicines free of charge from a community pharmacy of their choice (see annex 3.13 for service specification) (see annex 3.14 for list of ailments).

To join Pharmacy First, initially a patient had to collect a form at the GP surgery and then register at a participating pharmacy. Once signed up to a specific pharmacy, patients could then return to the same pharmacy if suffering from one of the minor ailments, without having to access the doctor.

The PCT agreed specific protocols and contract specifications in partnership with Erewash GPs and the community pharmacists offering the service. The protocols dictate the conditions that can be consulted for under Pharmacy First, as well as medication that can be issued and where a patient should be referred to an alternative health care professional. Self care information leaflets and advice from the pharmacist are also issued as part of the service. Free head lice combs are available to patients suffering from headlice.

The PCT monitors the consultation activity of Pharmacy First on a monthly basis using a specially designed database separate from the JUSC evaluation.

Again it was important to work with organisations in the community. Working closely with community pharmacists and general practitioners was essential. Sure Start Erewash helped by providing support and funding for patients using the service within the Sure Start area. This was helpful since the evaluation was concentrating on mothers and small children to help encourage behavioural change.

Some changes were made to Pharmacy First when it was rolled out to the South of Erewash (Long Eaton) in October 2005, including offering patients the opportunity to register direct at a pharmacy without having previously to visit a GP surgery. The roll-out was supported by a training event for pharmacists and GP practice staff held a month earlier.

The launches in July 2004 and October 2005 of Pharmacy First were promoted widely through the local press, posters and patient information leaflets sent to those on the distribution list with involvement also from Erewash Borough Council. (see annex 3.15 for Pharmacy First leaflets and posters)

During the period 1st April 2005 to 31st March 2006 there were 1,384 Pharmacy First consultations. The highest use of the scheme was for children aged 15 years or under.

Health information campaigns

This part of the module consisted of four seasonal campaigns as well as all-year distribution of two major DPP self care booklets "Better Health at Home and at Work" and "Caring for Kids". These booklets were distributed far and wide during the period of the Project with a total of 8,020 'Better Health at Home and at Work' and 10,806 'Caring for Kids' booklets scattered throughout Erewash (see annex 3.16 for the distribution details).

The first seasonal campaign began in April 2005 with the Summer Ailments campaign where 2050 leaflets were distributed. This was closely followed by the launch of the Hayfever campaign in May 2005 with a total of 1,575 leaflets distributed. From October 2005 until February 2006 the Winter Ailment campaign took place with a large distribution programme delivering 4,800 leaflets to over 45 venues. Finally, in January 2006 the Back to School campaign distributed 1600 leaflets mainly to Primary School children in Erewash using Health Promoting Schools networks. (See annex 3.17 for the module material and how you can obtain copies).

3.8 Training for Healthcare Professionals

3.8.1 Target health professional groups

The intention of the study was to engage with all primary care professionals and practice staff and where appropriate with secondary care consultants.

It became clear from the GPs that while they thought that self care is important they felt that their priorities lay in achieving DH targets and there were no targets around self care. It was necessary to make the case for self care as a tool to help meet national and local targets.

The new professional contracts provided the necessary rationale for the engagement of pharmacists and GPs in self care activities and their promotion. However, this appeared not to be an implicit understanding among the health professionals and it was necessary therefore to put the JUSC study into the context of the new contracts for both groups.

Pharmacists

The new pharmacy contract was designed to modernise pharmacy services and make better use of the skills and expertise of pharmacists and their staff giving the public more services and easier access to health improvement advice and services.

Support for self care is included in the pharmacy contract as an essential service with pharmacists expected to run six health campaigns to promote public health messages to

their users. JUSC provided the pharmacists in Erewash with materials to run seven promotional campaigns during the year, these were: four seasonal campaigns, prevention of CHD, better health at home and at work and back to school.

Under the new pharmacy contract pharmacists are also expected to offer lifestyle advice and sign-post users to the correct health source when appropriate. This function also allowed pharmacists to get involved in the JUSC "Staying well with asthma" campaign, directing those with asthma to information about the courses.

The PCT had a number of meetings with pharmacists in Erewash (18 pharmacies) beginning with letters to the Local Pharmaceutical Committee (LPC) and pharmacists in July 2004, (see annex 3.18 for correspondence to surgeries and pharmacies to gain engagement for JUSC) before the project began in Erewash. In November 2004 a more detailed letter was sent to community pharmacists and the LPC chair outlining the study and how it would benefit them. The PCT Self care Programme Manager also visited pharmacists and had face to face meetings to discuss the details of JUSC.

An evening event for pharmacists was also organised in August 2005 with presentations from the PCT Chief Executive, PAGB Steering Group, the Secretary of the Local Pharmaceutical Committee and the Chief Executive of the national body representing pharmacists in their contract negotiations (PSNC). The aim of the event was to place the role of the pharmacists in the context of not only JUSC but also the new pharmacy contract. It also provided a further opportunity for the local pharmacists to discuss the pharmacy minor ailment scheme (Pharmacy First) funded by the PCT.

Even though engagement had been slow, the project's objectives and aims were warmly welcomed by the profession in Erewash.

General Practitioners

Whilst the pharmacists had a great deal of self care included in their new pharmacy contract in 2005, before this in 2004 the new GMS contract (specifically sections 6.4 – 6.48) also provided an opportunity for more emphasis on self care in general practice. The Working in Partnership Programme was established to support general practice with the objectives defined in Chapters 6.4-6.48 of the GMS contract. With a budget of £10 million WiPP was tasked with the job of identifying and developing ways to manage workload in general practice. Indeed, JUSC found a natural home in this Programme and funds were allocated in 2004 to evaluate the JUSC Project.

Similar to the pharmacists, in July 2004, the PCT began to inform all the GPs in Erewash and the Local Medical Committee of the new self care programme being implemented in the area. This was followed by more briefing letters as well as a presentation by the PCT in October 2004 to the practice managers during a training day. The LMC were also enlisted to help to engage their members, with the Chair of the LMC sending out detailed letters about the benefits of the project, urging general practice staff to attend events organised by the PAGB and PCT.

An event was organised in early 2005 to involve practice staff, not only GPs, in the self care aware model of consultation. This was poorly attended by all staff as they were not convinced that they would learn anything new. In the event, the session was very valuable as it showed that there was a gap between what GPs, in particular, thought they were doing to support self care and what was actually in practice. As a result of this session and a subsequent session for GPs only, when a direction was given by the PCT to attend, the training and its delivery were focussed into the Local Enhanced Service agreement.

As one element of the JUSC project, the PCT commissioned three educational events for primary care teams, entitled "A partnership of experts - breaking the cycle of dependency", which was developed by Prof Mike Pringle in conjunction with Dr Peter Smith. At a pilot session involving a multi-disciplinary group in March 2005, the training materials were used to ensure understanding of the terminology and the approach. While members of the non-clinical staff were very positive, the GPs were of the opinion that they were not learning anything new and that they were already incorporating self care in their practice.

Following specific questioning around this, it became clear that there was no consistent approach within a practice, nor were the GPs able to confirm a coherent behaviour among all partners and staff in the practice around specific conditions. The most pertinent example was the response to the use of antibiotics across the GPs in a practice.

The JUSC project team amended the materials to include ways in which a practice could develop a consistent approach to prescribing, self care for long term conditions and the handling of advice for minor ailments.

The PCT developed a Local Enhanced Service (LES) under the new GMS contract to establish systematic approaches within general practices for the promotion of patient self care (see annex 3.19 for details). The specification is based on the Quality and Outcomes Framework points system for payment, with points being allocated for a series of indicators. For example, four points are given if the general practice agrees and utilises five locality based protocols each year for advice to patients on dealing with minor ailments/long term conditions within the practice and local pharmacies (see annex 3.20 for details of the GP self monitoring form). We are not aware of any other PCT which has introduced such an innovative scheme.

General Practice Local Enhanced Service (LES) to Promote Self Care:

Specification based on Quality & Outcomes framework
with financial incentives for GP practices to be proactive in offering
self care advice according to defined protocols

The self care aware model of consultation is another key indicator within the LES with four points being allocated once this is incorporated into routine patient consultations. The LES also specifies that all clinicians undergo training in the use of the self care model of consultation with a GP from each practice required to attend an educational training session with Prof Mike Pringle and then cascade this information to the remaining clinicians in the practice.

Three of these training events took place during the period of the JUSC project.

3.8.2 Educational events

The three educational events, called "A Partnership of Experts – Breaking the cycle of Dependency", were held on half days (2 hours 30 minutes) on:

- 15th June 2005, Risley Hall (20+ participants)
- 8th February 2006, Ilkeston Community Hospital (6 participants)
- 30th March 2006, Erewash PCT, Ilkeston (7 participants)

Although the format and content were similar for each, the invitation to the first was for interested practice teams and was intended mainly as an awareness raising exercise and was held before the LES was in place. Many of those who attended did so reluctantly at the explicit request of the PCT, which is an important finding in relation to training sessions generally. Without an understanding and acknowledgement of the reasons for attending a training session, it is counter-productive to issue a 'three line whip'.

The other two were linked to accreditation of the Locally Enhanced Services (a supplement to the new GMS Contract for involvement in self care) with one senior clinician per practice expected in accordance with the requirements of the agreement. These latter two were more events for skills training for cascading to practice team members.

The sessions were each led by Professor Mike Pringle, on behalf of Collingham Healthcare Education Centre, and his presentation and course notes have been made available to the JUSC team (available in annex 3.21).

The session objectives

The objectives of the sessions were to:

- Recognise the benefits of supporting self care
- Decide where the greatest potential lies
- Know how to support patients to become experts in their own healthcare
- Understand the nature of a "self care aware consultation"
- Identify and understand the barriers

The content

a) The meaning of self care

The first session introduced the concept of self care as a natural part of all our lives. The continuum from 100% self care (e.g. daily choices on what to eat) to 100% professional care (e.g. in intensive care) was illustrated as was the health care pyramid showing the impact that increased or decreased self care might have on primary care demand.

The literature was summarised. The main messages were that patients are skilled at self care and use it routinely, but do not get support in doing so from healthcare professionals. Two websites with further evidence were given:

www.dh.gov.uk/selfcare
www.wipp.nhs.uk

b) The self care vision

The first part of this session looked at consistency of messages. But getting group members to look at what advice they each gave for common symptoms in primary care, the variety of advice, policy and information was illustrated. The benefits of effective advice giving were linked into Prochaska and DiClementi's stages of change[28].

During the discussions participants accepted the importance of giving consistent messages / advice from all healthcare professionals and the way forward using practice protocols was raised. Involving others in the community when compiling self care protocols was recommended, including the local pharmacist. It was agreed that local knowledge of schemes and initiatives might also be helpful to recommend to patients.

They also noted the importance of supporting patients' self care decisions, although some felt that not all patients will be able to take on more self care. This latter point would be a topic of discussion among the practice team members when the 'trainer' ran his/her own session.

c) The self care aware consultation

After tea, the participants were invited to consider how they might use consultations to most effectively support self care. As part of understanding the patient's journey of care, and at the same time supporting their self care, the following key questions were highlighted, reinforced and used in team exercises:

[28] Prochaska JO & DiClementi CC. (1983) Stages and processes of self-change in smoking: toward an integrative model of change. *Journal of Consulting & Clinical Psychology*; 51(3): 390-395

- What have you already tried?
- How long have you tried this?
- What were you trying to achieve by doing/taking this?
- Has it worked and how?
- Have you stopped doing what you tried – and why?
- What could you do next time?

d) What is stopping it?

The final session looked at the possible blocks to supporting self care and how group members could overcome those blocks.

Discussions included the issue of the level of harm that can be done through healthcare professionals criticising their colleagues' methods of care to patients. This can also undermine the patient and lead to lack of confidence, which in turn can slow the progress the patient can make in taking greater responsibility for their health and symptoms and in using the expertise of other healthcare professionals than the doctor.

4. DATA COLLECTION & ANALYSIS

4.1 Patient Recruitment

Patients were recruited for the intervention groups as follows:

> ***Prevention of CHD module:*** via invitation contained in a CHD information pack distributed by community pharmacies, the PCT and local employers. Initially, a risk assessment "wheel" leaflet was distributed widely in the community to encourage people to then request an information pack. However, uptake via this route was low and invitations were subsequently issued directly by local employers to their workforce during June/July 2005 with the information pack provided to any respondents.
>
> ***Asthma module:*** via community-based promotion of the "Staying Well with Asthma" EPP-based programme and GP invitation to adults diagnosed with 'active' asthma i.e. who had recognised Read codes for asthma on their medical records and had received asthma medication within the last 12 months. Recruitment of the GP samples took place via nine practices during April-July 2005; respondents were allocated to the intervention or control group depending on whether they were willing to attend the 7 week EPP course. In addition respondents were recruited via community-based promotion of two half day asthma self care sessions held in September and November 2005.
>
> ***Minor Ailments module***: via GP invitation to a sample of mothers whose children were registered for the "Pharmacy First" scheme at one of five GP practices in Ilkeston, or one of four practices in Long Eaton. These invitations were issued over the period April-August 2005 in Ilkeston and December 2005 in Long Eaton.

A study information sheet was sent as part of the invitations. If willing to participate in the study, respondents were asked to sign a consent form, enclosed in the same pack. Pre-paid envelopes were provided for them to respond to the invitation and return their consent forms to the PCT.

Patients were recruited for the control groups as follows:

> ***Prevention of CHD control (at follow-up only):*** via a market research company (2Europe) undertaking in-home interviews with a sample of the general population aged over 30 years who had not participated in the CHD self care initiative, plus a booster sample of mothers aged 20-29 years. As part of this research component, the general level of awareness of the self care programme as a whole, and any changes in use of sources of healthcare advice, were also evaluated.
>
> ***Asthma control:*** via GP invitation letter at baseline to adults with 'active' asthma who were willing to participate in this evaluation but did not wish to

attend the sessions in the "Staying Well with Asthma" programme (either the EPP–based course or the half day sessions).

Minor Ailments control: via GP invitation letter at baseline to a sample of mothers whose children were not registered for the Pharmacy First scheme. These were all sampled from three practices in the Long Eaton area where Pharmacy First was not promoted until October 2005.

The overall recruitment process is summarised in Figures 4.1, 4.2 and 4.3 below.

Figure 4.1: CHD Survey - Baseline Recruitment

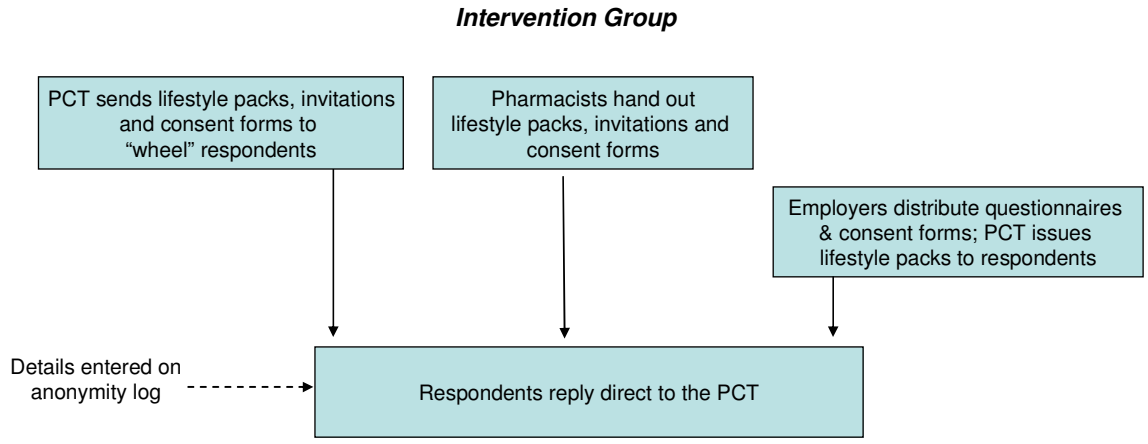


Figure 4.2: Asthma Survey - Baseline Recruitment

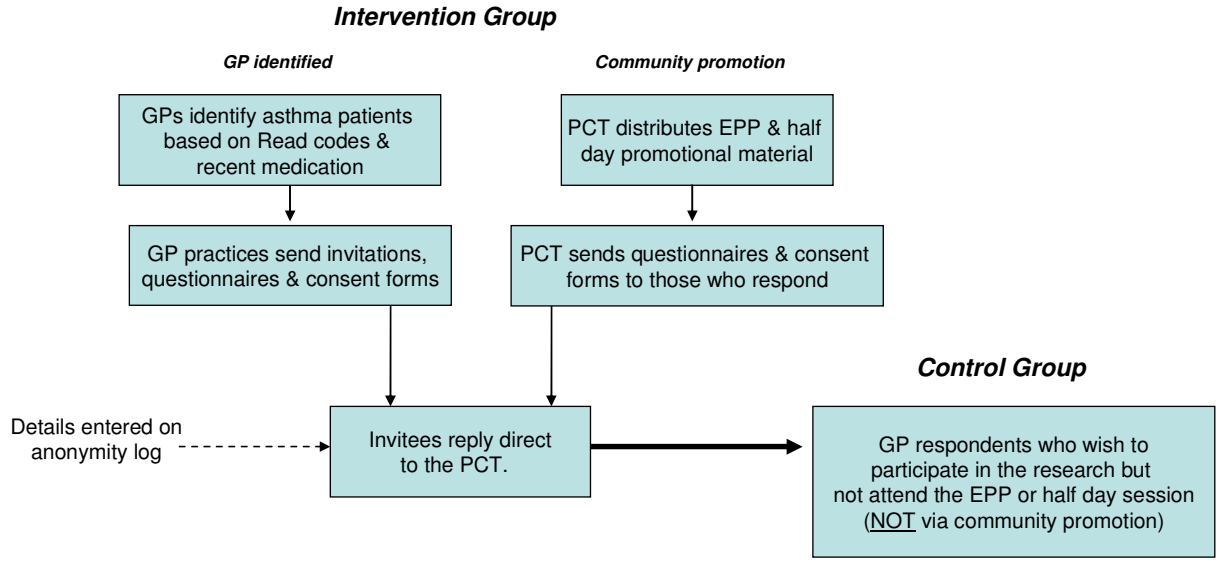
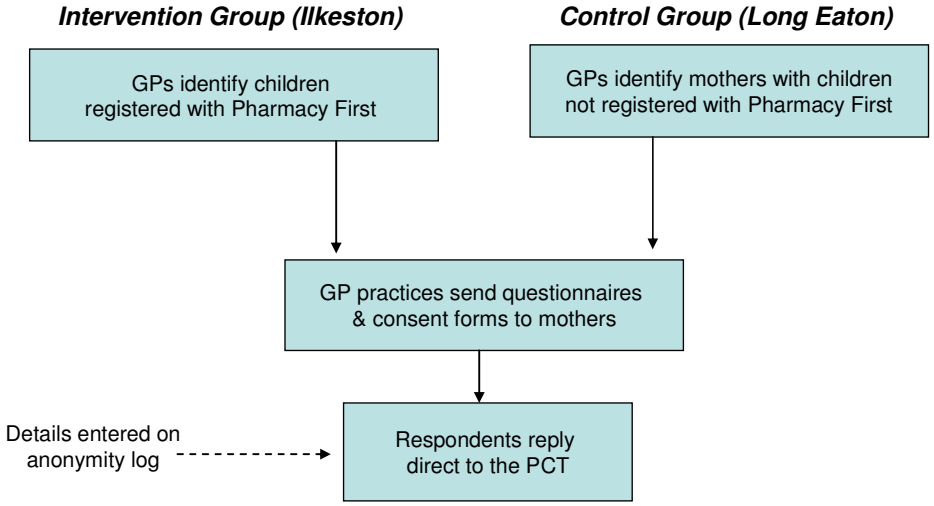


Figure 4.3: Minor Ailments Survey - Baseline Recruitment



4.2 Baseline Data Collection

There were some difficulties in recruiting the target participant numbers for all three intervention groups. The original target numbers were based on speculative assumptions regarding likely take-up of the interventions, but this was unknown at the time of protocol development.

Table 4.1 summarises the target and achieved recruitment numbers at baseline.

Table 4.1: Baseline Recruitment Numbers

	Intervention Groups		Control Groups	
	Target	**Achieved**	**Target**	**Achieved**
CHD Module	500	270	n/a	n/a
Asthma Module	100	83	100	213
Minor Ailments Module	200	121	200	215

The hypothesis for the CHD module was that a larger proportion of those who received the advice packs would change their self care behaviour over the intervention period, as compared to the control group in the general population. If 20% of the CHD intervention group reported a change in behaviour, compared to no change in the control group, the margin of error would be 5.1% for a sample of 250, compared to 3.6% for a sample of 500.

The sample size for the asthma module was driven by the number of participants in the "Staying Well with Asthma" programme. Although it was anticipated this might be approximately 100 in total, this was also unknown when the protocol was developed.

Using the same 20% assumption regarding behavioural change as for the CHD module, the margin of error is 8% for a sample of 100. However, the pre and post programme assessments (based on the EPP and Asthma UK questionnaires) focus on attitudinal data for which formal statistical power calculations were not appropriate.

For the minor ailments module, a sample size was calculated statistically for the possible change in GP consultation rates. The hypothesis was that promotion and expansion of the Pharmacy First scheme would be associated with a reduction of 20% in GP consultations amongst the group registered with the scheme. To achieve a 5% level of significance and 90% power, a minimum of 153 carers in each of the minor ailments intervention and control groups would be required.

Baseline data were collected via postal questionnaires for each of the achieved patient samples shown in Table 4.1. A serial number was assigned to each questionnaire distributed and the returned questionnaires were logged against those numbers; only PCT staff were aware of the identity of anyone invited to participate.

The earliest responses to the CHD baseline questionnaire were received in February 2005; the latest responses were received following the questionnaire distribution by employers in June/July, following which the CHD advice packs were issued. One result of this was that the intervention group includes respondents who received the lifestyle advice pack up to seven months apart. However, the follow-up questionnaires were issued in two waves, February and March 2006, in part reflecting this difference, and these questionnaires all refer to CHD prevention behaviour in the "past 6 months".

Baseline data collection for the Minor Ailments module continued from March to December 2005 (longer than anticipated) due to difficulties in recruitment. Again, one effect of this was that some intervention group participants who responded early in the process were exposed to the Pharmacy First intervention for 12 months or more, whereas some who responded towards the end of the baseline data collection period were exposed for only 3 months.

Telephone interviews with 64 health professionals were undertaken by PMSI Healthcare in January/February 2005 (GPs, pharmacists, practice nurses, district nurses, health visitors and school/nursery nurses).

4.3 Follow-up Data Collection

Follow-up data collection consisted of postal survey questionnaires to all baseline respondents, plus on-site questionnaires distributed to the EPP participants at the last (asthma-specific) session, focus groups with mothers of children registered (intervention) or not registered (control) with Pharmacy First, and record audits in the Minor Ailments module.

The first wave of follow-up questionnaires was issued by post in February 2006 to participants in the CHD module who had returned their baseline questionnaires by the

end of June 2005. Further waves of follow-up questionnaires were issued to other participants in all three modules during April 2006.

Response rates for both baseline and follow-up surveys are given in Table 4.2. The follow-up response rates were particularly high, ranging from 71% to 92%.

The CHD control group was recruited by the market research company 2Europe (www.2europesolutions.co.uk). 500 in-home interviews were undertaken with this group in April 2006. In addition a further 40 in-home interviews were undertaken with mothers aged 20-29 years (to inform the Minor Ailments module).

Table 4.2: Postal Survey Response Rates

	Baseline		Follow-Up	
	Questionnaires Issued n	Response n (%)	Questionnaires Issued n (d)	Response n (%)
CHD Intervention	1,395	270 (19%)	245	178 (73%)
Asthma Intervention	1,771 (a)	83 (5%) (b)	83	76 (92%)
Asthma Control		213 (12%)	158	112 (71%)
Minor Ailments Intervention	556	121 (22%) (c)	121	92 (76%)
Minor Ailments Control	779	215 (28%) (d)	190	149 (78%)

(a) Asthma intervention and control groups were not pre-selected
(b) Respondents who attended an intervention session
(c) Respondent mothers, excluding duplicate responses for multiple children
(d) Follow-up questionnaires were only issued to baseline respondents who provided address details

Four focus groups with mothers in the target group for Pharmacy First were conducted by PMSI Healthcare in late March 2006. Two of these groups were with mothers whose children were registered with Pharmacy First, and two groups with mothers whose children were not registered.

GP and Pharmacy First record audits for 83 intervention participants and matched controls in the Minor Ailments module were undertaken in March/April 2006. These audits examined consultation and prescribing rates for conditions covered by Pharmacy First in the six months following registration (for the intervention group) compared with the equivalent six months in the previous year. For the control group, a fixed six month period (1st June-30th November) was compared between 2004 and 2005.

Telephone interviews were undertaken in May/June 2006 with a sample of 51 health professionals equivalent to that at baseline. In addition, interviews were undertaken with practice managers and relevant members of the PCT's management team.

4.4 Data Analysis Plan

For the Minor Ailments and Asthma modules, the socio-demographic characteristics of the intervention and control samples at baseline were compared. Statistically significant variance were assessed and discussed with the Steering Group.

Once follow-up responses had been received, the control sample was matched to the intervention sample in each module (Asthma or Minor Ailments) on a number of key socio-demographic variables considered important by the Steering Group, in order to normalise for the possible effect of those variables on the outcomes of interest. This was facilitated by the control sample being larger than the intervention sample in each module, enabling a matched pair to be identified for each intervention respondent.

Following completion of this process, analysis focused on change between baseline and follow-up in the intervention group compared to change in the control group. This involved a comparison of two longitudinal measures for which a parametric statistical test, the paired t-test, was used. This was seen as the most important comparison for the overall evaluation of JUSC and applied to most of the data, for which means could be calculated.

In addition, cross sectional comparisons between the intervention and control groups were undertaken (at baseline and follow-up separately), for which a chi-squared statistical test was used. A chi-squared test was also used for data reporting frequencies or proportions.

Statistical significance was estimated at the 5% level (so p values <0.05 represent significant differences between the intervention and control groups or between baseline and follow-up for an individual group).

Health professional attitudes, PCT management attitudes and focus group data on the Minor Ailments module were analysed qualitatively. The focus group data were coded from audio tapes using Atlas software.

Data analysis was undertaken by PMSI Healthcare.

5. EVALUATION OF INTERVENTIONS IN CORONARY HEART DISEASE

5.1 Key Outcome Measures

- Uptake of diet change, exercise, smoking cessation and reduced alcohol consumption
- Consultation rates with health professionals regarding heart health

5.2 Summary & Implications

We compared those who took up this intervention against controls who did not, concentrating on CHD risk reduction actions taken in the six months prior to the follow-up survey.

The following were the findings against our key outcome measures:

- 67% of the intervention group reported reducing the amount of saturated fat in their diet compared to 20% in the control group
- 47% of the intervention group increased their physical exercise compared to 10% in the control group
- 37% of the intervention group reduced their alcohol intake compared to 6% in the control group
- Amongst the subgroup of smokers, a third of the intervention group gave up compared to 5% in the control group, although the subgroups were substantially different in size (intervention n=12, control n=168)
- 22% of the intervention group visited their GP in relation to heart health compared to 9% of the control group.

The key implications are:

- We had a self selected group who took up the intervention, but those who took up the intervention showed a marked increase in healthy behaviours affecting their risk of CHD
- Approaching through employers was effective in generating interest
- We had most uptake among the more affluent and those with existing awareness of risk factors, but we were less successful in achieving wider community involvement
- Extending CHD prevention outside the NHS, especially to those with lower awareness of risk factors, is critical to changing behaviour at the community level

5.3 Activity Overview

As outlined in Chapters 2 and 3, the coronary heart disease (CHD) interventions were as follows:

- Distribution of lifestyle advice packs, in response to requests from people using the CHD risk assessment "wheel" device and employees returning questionnaires distributed through their employers;

- Promotional events throughout the PCT, including local poster and media campaigns promoting heart health.

As outlined in Chapter 4, the evaluation comprised:

- Postal survey of recipients of the lifestyle advice pack at baseline and follow-up (intervention group)
- In-home interviews amongst a community sample who had not received the pack at follow-up (control group).

5.4 Sample Profile & Baseline Characteristics

The baseline survey generated 270 intervention respondents. Control group respondents were not recruited at baseline because this module was aimed at disease prevention in the general adult population and it was important that the control group should be unaware of the programme. Collecting retrospective data on behavioural change at follow-up amongst a wide community sample unaware of the programme was therefore considered the most appropriate method of establishing a control sample.

Outline profile details for the intervention group are given in Table 5.1 below. This shows that the sample was predominantly female, owning their own property and in paid employment.

Table 5.1: CHD Survey - Baseline Sample Profile

Baseline sample profile	Intervention
Number of respondents	270
Gender:	
Male (%)	69 (25.56%)
Female (%)	201 (74.44%)
Mean age (SD)	47.22 (SD 13.96)
Has long term illness (%)	102 (37.78%)
Own property (%)	238 (88.15%)
In paid employment (%)	206 (76.30%)
Current smoker (%)	26 (9.63%)

Of the 102 respondents reporting having a long term condition, the most common was high blood pressure (44%), followed by asthma (28%), heart disease or angina (11%) and diabetes (7%).

When asked specifically about their blood pressure, 8% of the total sample (n=270) said it was "high" and 13% said it was "slightly raised" (whether or not controlled by medication), a total of 21%. This compares with 17% (45/270) who reported a long term condition as being diagnosed with raised blood pressure (unprompted).

68% of the total sample had had their blood pressure tested in the previous 6 months, overwhelmingly at a GP practice. 26% had had their cholesterol tested in the previous 6 months, again most commonly at the GP practice. Consumption of high cholesterol food was similar between men and women with most saying they eat "some" specified fatty foods, although slightly more women claimed to eat "little" of these foods.

13% of men and 11% of women reported regular consumption of more than 21 units of alcohol per week for men or 14 units for women. 25% of the sample took physical exercise less than once per week (defined as one 30 minute or longer episode or two 15 minute episodes of brisk walking, jogging, cycling, swimming or similar).

20% of the baseline sample had visited their GP in the previous 6 months in relation to their heart health, and 79% had thought about their lifestyle in relation to heart health. However, seeking advice from a pharmacist, buying OTC medication or calling NHS Direct in relation to heart health was negligible.

5.5 Comparison of Baseline & Follow-up Measures

5.5.1 Follow-up sample profile

The follow-up survey generated 178 intervention respondents (73% response) and 540 control respondents. The control group was a community-wide sample drawn from in-home interviews undertaken by the market research company 2Europe.

These two samples were not matched for socio-economic variables as data on individual respondents for the control sample cannot be made available by 2Europe according to the Market Research Society Code of Conduct. Table 5.2 shows that the gender split is similar but mean age is slightly higher in the intervention group. The socio-economic variables show some differences; in particular the intervention group has a higher proportion who own their own property and a higher proportion in paid employment.

The intervention group also has a higher proportion reporting having a long term condition and a lower proportion who are current smokers. It should be recognised that the proportion of the intervention group who are current smokers may reflect a self-selection bias. The control group by contrast was not recruited with any reference to heart disease, so smokers may have been less likely to have been deterred from responding in the control sample.

7.4% (40/540) of the control group had been treated in hospital in the previous 6 months, 45% of whom stayed one or more nights and 40% of whom visited an outpatient department. Although this question was not asked of the intervention group, the much higher proportion of respondents with a long term condition (compared to the control group) suggests that the intervention group are likely to have had a higher interaction with health services at both baseline and follow-up.

Table 5.2: CHD Survey – Follow-up Sample Profile

Follow-up sample profile	Intervention	Control
Number of respondents	178	540
Gender:		
Male (%)	44 (24.72%)	123 (22.78%)
Female (%)	134 (75.28%)	417 (77.22%)
Mean age	51.45 (SD 12.9)	46.36 (SD 14.0)
Has long term illness (%)	61 (34.27%)	103 (19.07%)
Own property (%)	159 (89.33%)	309 (57.22%)
In paid employment (%)	125 (70.22%)	294 (54.44%)
Current smoker (%)	8 (4.49%)	160 (29.63%)

5.5.2 Awareness of JUSC

At follow-up, there was significantly more awareness of the JUSC programme (described as "any self care programmes being promoted locally") in the intervention group as compared to the control group. Table 5.3 shows that this higher awareness was reported across both genders and all age groups. Over half the intervention group were aware of local self care programmes and 40% were aware of "something to do with heart disease".

Table 5.3: Awareness of Self Care & CHD Promotion

Are you aware of any "self care" programmes being promoted locally in the last few months?		Total		Male		Female		<45		45-64		65+	
		Intervention	Control	Intervention	Control	Intervention	Control	Intervention	Control	Intervention	Control	Intervention	Control
Yes	*pop*	173	540	43	123	130	417	55	266	91	218	27	56
	n	90	18	20	2	70	16	26	8	47	8	17	2
	%	52.02%	3.33%	46.51%	1.63%	53.85%	3.84%	47.27%	3.01%	51.65%	3.67%	62.96%	3.57%
No	*pop*	173	540	43	123	130	417	55	266	91	218	27	56
	n	83	522	23	121	60	401	29	258	44	210	10	54
	%	47.98%	96.67%	53.49%	98.37%	46.15%	96.16%	52.73%	96.99%	48.35%	96.33%	37.04%	96.43%
P-value (intervention vs control)*		<0.001		<0.001		<0.001		<0.001		<0.001		<0.001	
Which "self care" programmes being promoted locally have you been aware of in the last few months?		Total		Male		Female		<45		45-64		65+	
		Intervention	Control	Intervention	Control	Intervention	Control	Intervention	Control	Intervention	Control	Intervention	Control
Something to do with heart disease/heart health	*pop*	178	540	44	123	134	417	55	266	96	218	27	56
	n	71	7	15	1	56	6	18	2	42	4	11	1
	%	39.89%	1.30%	34.09%	0.81%	41.79%	1.44%	32.73%	0.75%	43.75%	1.83%	40.74%	1.79%
P-value (intervention vs control)*		<0.001		<0.001		<0.001		<0.001		<0.001		<0.001	

** Any value < 0.05 is statistically significant to the 5% level*

A few intervention group respondents (n=14) said they had not completed the baseline questionnaire (described as the Erewash "Heart-to-Heart" coronary heart disease risk assessment questionnaire) but this was a recall problem since the database does contain

their baseline responses. The time lag between baseline and follow-up (up to 11 months) obviously may have affected this.

5.5.3 Attention to lifestyle

At follow-up, more than three quarters of the intervention group had thought about their lifestyle in relation to their own heart health and/or a partner, family member or friend's heart health in the previous six months. This is significantly higher than the equivalent proportions in the control group. (Table 5.4)

However, it should be noted that the baseline intervention group sample (n=270) was also asked "Have you thought about your lifestyle prior to the 'Heart to Heart' assessment?" 78.5% of baseline respondents said they had thought about their lifestyle. It is therefore possible that the intervention group was generally more thoughtful than the control group regarding their lifestyle, independently of the health promotion and lifestyle advice provided as part of the JUSC programme.

These findings may therefore support the argument advanced by some healthcare professionals (see Section 8.2) that it is particularly difficult to reach less motivated individuals. The CHD module as part of JUSC may have been successful in targeting individuals who were already thinking about their lifestyle, but it remains difficult to engage with those who are not thinking about these issues. Having said that, specific actions resulting from this thinking have shown clearly positive results in the intervention group (see section 5.2.4).

Table 5.4: Lifestyle Attention in Relation to Heart Health

Over the past 6 months have you:		Follow-up	
		Intervention	Control
Thought about your lifestyle in relation to your own heart health	pop	175	538
	n	137	66
	%	78.29%	12.27%
	p-value*	<0.001	
Thought about the lifestyle of a partner, adult family member or friend in relation to their heart health	pop	174	538
	n	132	60
	%	75.86%	11.15%
	p-value*	<0.001	

* Any value < 0.05 is statistically significant to the 5% level

5.5.4 CHD preventative actions

Preventative actions were assessed retrospectively by means of survey questions related to "the last 6 months". Table 5.5 shows that on all the lifestyle dimensions of smoking, alcohol consumption, physical exercise and saturated fat intake a significantly higher proportion of the intervention group had taken action which would help to reduce their risk of CHD.

However, as indicated above these were not matched samples. In particular the much higher proportion of the intervention group who gave up smoking should be viewed in the light of the much lower baseline numbers who were smokers.

Self selection bias in the context of preventative health strategies may be a natural consequence of health promotion, which inevitably elicits responses from more motivated individuals. It is also possible that the intervention group respondents gave answers to these questions which they considered to be the "right" answers versus their baseline responses. Nevertheless, the findings do suggest that the level of activity relating to all four modifiable CHD risk factors was significantly higher in the intervention than in the control group – ie. higher in those exposed to specific CHD lifestyle advice than those not exposed to such advice.

Table 5.5: Lifestyle Actions in the Last 6 Months (prompted)

Over the past 6 months have you:		Follow-up	
		Intervention	Control
Given up smoking	pop	12	168
	n	4	8
	%	33.33%	4.76%
	p-value*	<0.001	
Reduced the amount of alcohol you regularly drink	pop	157	538
	n	58	31
	%	36.94%	5.76%
	p-value*	<0.001	
Increased the amount of physical exercise you do per week	pop	176	538
	n	82	52
	%	46.59%	9.67%
	p-value*	<0.001	
Reduced the amount of saturated fatty food you eat	pop	177	538
	n	118	107
	%	66.67%	19.89%
	p-value*	<0.001	

* Any value < 0.05 is statistically significant to the 5% level

Respondents were also asked an open-ended question at follow-up to see if they had changed anything else in relation to their lifestyle. This shows that there was a significant focus on diet and exercise in the intervention group compared to the control group. (Table 5.6)

Table 5.6: Other Lifestyle Actions in the Last 6 Months (unprompted)

In the past 6 months have you changed anything else in the last 6 months? *NB. Free text answers grouped according to subject*		Follow-up	
		Intervention	Control
Change in diet	pop	178	540
	n	20	36
	%	11.24%	6.67%
	p-value*	0.049	
Change in exercise routine	pop	178	540
	n	12	8
	%	6.74%	1.48%
	p-value*	<0.001	
Lost weight	pop	178	540
	n	5	5
	%	2.81%	0.93%
	p-value*	0.063	
Other	pop	178	540
	n	11	17
	%	6.18%	3.15%
	p-value*	0.070	

* Any value < 0.05 is statistically significant to the 5% level

5.5.5 Use of health services

Respondents' use of primary care health services was examined in the same way as lifestyle actions, ie. retrospectively for the previous six months. However, for these measures there are also directly comparable baseline data available for the intervention group.

Comparing baseline and follow-up measures for the intervention group, there are no significant differences in the proportion who have visited their GP, sought advice from a pharmacist, or called NHS Direct in relation to their heart health or bought a statin or other heart medicine on an OTC basis. (Table 5.7) In addition to these data, 1% of the control group had bought aspirin for their heart.

However, comparing the intervention and control groups at follow-up, there is a very significant difference in the proportion who have visited their GP in relation to heart health. Whilst this proportion did not increase significantly between baseline and follow-up in the intervention group, at 22.5% it is more than double that in the control group at follow-up. (Table 5.7)

This difference might be expected based on the different characteristics of the intervention and control groups in terms of long term condition. This finding may also reflect the fact that the intervention group were more "CHD aware" at baseline and this awareness continued through to the follow-up.

There were no other significant differences between the intervention and control groups in use of primary care services at follow-up.

Table 5.7: Use of Primary Care Services

In the past 6 months have you done any of the following in relation to your heart health:		Baseline	Follow-up	
		Intervention	Intervention	Control
Visited your GP	pop	178	178	540
	n	42	40	49
	%	23.60%	22.47%	9.07%
	p-value*		<0.001	
		0.801		
Sought advice from a pharmacist	pop	178	178	540
	n	2	3	4
	%	1.12%	1.69%	0.74%
	p-value*		0.266	
		0.652		
Called NHS Direct	pop	178	178	540
	n	0	2	1
	%	0.00%	1.12%	0.19%
	p-value*		0.092	
		0.156		
Bought a statin or other heart medicine without prescription	pop	178	178	540
	n	0	2	2
	%	0.00%	1.12%	0.37%
	p-value*		0.242	
		0.156		

* Any value < 0.05 is statistically significant to the 5% level

The analysis reported in Table 5.7 was also undertaken excluding respondents with a long term condition and the same results in terms of significance were found.

5.5.6 Blood pressure & cholesterol testing

There was no significant difference between baseline and follow-up in terms of the proportion of the intervention group who had had their blood pressure or cholesterol tested in the previous six months.

However, there were significant differences at follow-up between the intervention and control groups. Table 5.8 shows that nearly two thirds of the intervention group had had their blood pressure tested (similar to the proportion at baseline) compared to less than a quarter in the control group. The proportion of the intervention group who had had their cholesterol tested (26%) was double that in the control group.

Table 5.8: Blood Pressure & Cholesterol Testing

In the past 6 months have you done any of the following in relation to your heart health:		Baseline	Follow-up	
		Intervention	Intervention	Control
Had your blood pressure tested	pop	178	175	540
	n	118	114	129
	%	66.29%	65.14%	23.89%
	p-value*		<0.001	
		0.820		
Had your cholesterol tested	pop	177	176	540
	n	53	46	70
	%	29.94%	26.14%	12.96%
	p-value*		<0.001	
		0.426		

* Any value < 0.05 is statistically significant to the 5% level

In all cases the dominant place where these respondents had their blood pressure or cholesterol tested was the GP surgery.

5.6 Community-wide Attitudes at Follow-up

The community survey by the market research company 2Europe found that 4% of the 540 respondents recalled seeing the risk assessment "wheel" when prompted by being shown it, plus a further 3% who were unsure. Recall was highest amongst females without children (8% prompted recall).

Overall, 3% of the 2Europe sample were aware of any self care programmes being promoted locally. Of those who recalled any programme (n=18) from the last few months, 39% recalled "something to do with heart disease". This, along with "something to do with asthma", was the highest level of prompted recall of any of the options given.

11% of the 2Europe sample were aware of product advertising or general promotion campaigns relating to heart health (compared with 51% of the intervention group). If breakfast cereals are included, 56% of the control group awareness was concerned with healthy eating. 5% was related specifically to cholesterol, 4% to smoking and 2% to exercise. Awareness was highest (19%) amongst those who reported having a long term condition.

9% of the 2Europe sample had bought cholesterol-reducing foods in the previous 6 months, 38% of whom had done this as a result of medical advice (26% because they thought it was "good for you").

By contrast, only 13% of those who had reduced their alcohol consumption and none of those who had increased their physical activity had done so as a result of medical advice. The strongest reasons were self interest in the form of wanting to make their own lifestyle change, wanting to take up more walking/dancing/swimming, wanting to lose weight or to feel good/look good.

Only 1.3% of the 2Europe sample had thought about changing the way they used health services generally (not just for heart health) in the previous six months. This compares with 20.6% of the intervention group ($p<0.001$).

This last finding suggests that, even if the intervention group were self-selected and consequently more "CHD aware" at baseline, they still appeared to change their healthcare-seeking attitudes at a general level, as well as taking action on specific modifiable CHD risk factors, following the JUSC programme.

6. EVALUATION OF INTERVENTIONS IN ASTHMA

6.1 Key Outcome Measures:

- Participation levels in the "Staying Well with Asthma" programme
- Participants' attitudes towards taking care of their asthma and that of any other family members
- Asthma medication usage
- GP consultation rates for asthma

6.2 Summary & Implications

We compared those who took up this intervention against controls who did not.

The following were the findings against our key outcome measures:

- In total 83 people participated in the intervention, of whom 30 attended a seven week EPP course. Half day asthma taster sessions were also run and these were effective at recruiting participants to the EPP
- GP consultation rates increased in the intervention group; this may be associated with the poorer levels of asthma care seen at baseline compared with the controls, and also the higher level of change in their condition (at follow-up) as perceived by the intervention participants
- Participants in the intervention group increased their appreciation of other things they could do to take care of their asthma and became less worried about the side effects of medication
- At follow-up, patients in the intervention group were more likely to be confident about discussing asthma with their GP and to ask questions. The EPP and the half day session did not change overall attitudes towards coping with or wanting to take control of asthma though given the short time span between baseline and follow-up it is not possible to draw definitive conclusions.

The key implications are:

- Recruiting to an EPP in a PCT which does not yet have well established community contacts and networks requires significant input from the PCT both in terms of organisation and explanation
- Unsurprisingly, recruiting participants for half day asthma sessions was much easier than for the seven weeks of an EPP with a session on asthma
- Because there were 30 participants (compared with the target of 100 for the EPP course) and the time gap between baseline and follow-up was much shorter than originally planned, it is not possible to make any quantitatively definitive conclusions about the effectiveness of the course. Qualitative

findings of JUSC however strongly suggest that EPP courses can have a positive impact on participants.

6.3 Activity Overview

As outlined in Chapters 2 and 3, the asthma intervention was as follows:

- Promotion and recruitment to an EPP course comprising six generic sessions plus one asthma-specific session, under the title "Staying Well with Asthma"
- Promotion and recruitment to three stand-alone half day asthma sessions which included a "taster" on the EPP.

As outlined in Chapter 4, the evaluation comprised:

- Postal survey of EPP and half day session participants and controls at baseline and follow-up
- Pre and post session questionnaires issued at the final (asthma-specific) EPP session

6.4 Sample Profile & Baseline Characteristics

The baseline survey generated 101 intervention respondents and 213 control respondents. Outline profile details are given in Table 6.1 below.

Table 6.1: Asthma Survey - Baseline Sample Profile

Profile of all respondents at baseline	Intervention	Control
Number of respondents	101	213
Gender (%)		
Male	28 (27.72%)	73 (34.27%)
Female	59 (58.42%)	106 (49.77%)
Unknown	14 (13.86%)	34 (15.96%)
Mean age (SD)	56.7 (SD 12.7)	51.6 (SD 15.5)
Have a child with asthma (%)	15 (14.85%)	45 (21.13%)
Do not own their accommodation (%)	14 (13.86%)	32 (15.02%)
Not in paid employment (%)	60 (59.41%)	107 (50.23%)

The follow-up survey generated 76 intervention respondents (63% response) and 112 control respondents (52% response). The control sample was matched to the intervention sample on the variables shown in Table 6.1, resulting in the profile given in Table 6.3. These were the samples used for analysis of the change between baseline and follow-up.

After matching for age and employment status, the intervention and control groups were very similar at baseline. A slightly smaller proportion of the intervention group had a child with asthma (15%) and did not own their accommodation (14%).

Respondents in the intervention group were slightly more anxious about their health in general and concerned about their asthma, but there were no significant attitudinal differences. Levels of social and work-related limitation were similar in the two groups.

Methods of self care of asthma were also similar in the two groups, but a higher proportion of the intervention group said they seek out information to help take care of their asthma (45% said they do this a great deal or a fair amount).

The intervention group also reported greater use of practice nurse and hospital services (Table 6.2). A slightly higher proportion of the intervention group visited a GP, compared to the control group, but there was a slightly lower mean number of visits in the intervention group.

Table 6.2: Baseline Use of Health Services in Last 3 Months

	Intervention	Control
Number of matched respondents	83	83
Visited GP	40 (48.2%)	39 (47.0%)
Visited practice nurse	24 (28.9%)	19 (22.9%)
Visited hospital OPD	4 (4.8%)	2 (2.4%)
Visited A&E	1 (1.2%)	0
Mean no GP visits (SD)	0.89 (1.28)	0.93 (1.67)
Mean no practice nurse visits (SD)	0.54 (1.30)	0.27 (0.52)

Although these differences were not statistically significant, they do suggest there was potential for improved control of asthma among the intervention group. This was confirmed after matching the two samples based on respondents at follow-up (n=76): the mean GP visits were 0.92 (SD 1.30) in the intervention group compared to 0.58 (SD 1.05) in the control group at baseline (p=0.077), and this gap widened to 1.30 (SD 1.84) and 0.46 (SD 1.03) at follow-up ($p < 0.001$).

The most common reason for intervention group respondents seeing health or social care professionals was a chest infection (compared to breathlessness for the control group). This indicated that participants in the intervention group saw a professional for the 'right' reasons! There was strong agreement between the groups on attitudes towards health professionals regarding asthma and levels of confidence in consultation, but confidence with pharmacists was generally lower than with GPs or nurses.

At baseline, the intervention group respondents made slightly greater use of asthma reliever medication (mean inhaler use 2.5 times per day compared to 2.2 times per day for the control group, n=76) and preventer medication (2.1 times per day compared to 1.7) although these differences were not statistically significant.

In the event, 83 of the intervention sample subsequently attended an EPP programme or half day asthma session. 30 of the intervention group participated in the 7 week EPP course, 17 of whom also attended one of the stand-alone half day sessions. The balance of the intervention group (n=53) attended a half day session only.

6.5 Comparison of Baseline & Follow-up Measures

6.5.1 Follow-up sample profile

Of the 83 intervention participants, follow-up responses to the postal survey were received from 76 (91.6%). These were matched with respondents from the control group on age and employment status. The profile of this follow-up sample is given in Table 6.3 overleaf.

The mean age of 58 is slightly higher than the mean age for the baseline intervention and control groups (Table 6.1), reflecting the composition of attendance at the intervention sessions. It proved particularly difficult to attract younger adults to these sessions. The intervention group were also slightly more disadvantaged than the control group (as indicated by the proportion not owning their own accommodation).

Table 6.3: Asthma Survey - Follow-up Sample Profile

Profile of paired respondents at follow-up	Intervention	Control
Number of respondents	76	76
Gender (%)		
Male	23 (30.26%)	28 (36.84%)
Female	53 (69.74%)	48 (63.16%)
Mean age (SD)	58.13 (SD 12.5)	58.01 (SD 12.6)
Have a child with asthma (%)	8 (10.53%)	14 (18.42%)
Do not own their accommodation (%)	12 (15.79%)	5 (6.58%)
Not in paid employment (%)	52 (68.42%)	40 (52.63%)

As at baseline, the intervention group reported more asthma-related symptoms and more limitation on their activities “during the last two weeks” than the control group.

There was a decline in both groups on three symptom measures (breathlessness, wheezing and chest heaviness/tightness) and a decline in the control group on coughing (versus an increase in the intervention group), but none of these differences were significant. There was also a slight decline in limitation on strenuous and moderate activities in both groups, but again this was non-significant.

It is possible that the general decline in symptoms and reduction in limitations compared to the baseline survey reflects a change in the weather or general environment (eg. pollution).

6.5.2 Attitudes towards asthma management

There were no significant differences between the intervention and control groups in terms of change (follow-up versus baseline) in overall attitudes to their health, anxiety about, coping or wanting to take control of their asthma, perceptions of other people's understanding of their asthma, or judging when they need to see a doctor. There were also no significant differences between the groups in terms of change in their levels of concern, frustration or limitations on activity due to asthma. However no statistical generalisations can be made about the effectiveness or non-effectiveness of the intervention due to low number of participants (30 compared with the target of 100) and the short time span between intervention and follow-up. There is however good evidence that the type of courses being run in EPP lead to people feeling more in control of their condition, resulting in reduced use of health services and lower treatment costs. Evidence from internal monitoring of the national programme demonstrates that EPP can lead to decrease in severity of symptoms, greater control and reduction in use of care services.[29]

However, intervention group respondents became significantly more confident in asking their GP questions about asthma. They also became more confident in discussing their asthma openly in GP consultations, although the level of significance was borderline (Table 6.4). However, quantitative conclusion cannot definitively be drawn nor generalisations made to say whether the difference between intervention and control groups was because of the intervention. On the other hand, positive health outcomes for participants are more clearly demonstrated by the qualitative findings of the study.

Table 6.4: Change in Confidence in GP Consultations
(1=never; 6= all the time)

		Baseline		Follow-up		Change		P-Value change (Int vs ctl)*
		Intervention	Control	Intervention	Control	Intervention	Control	
When I see my GP I feel confident to discuss my asthma openly.	*n*	64	64	64	64	64	64	0.053
	Mean	5.58	5.78	5.75	5.69	0.17	-0.09	
	SD	0.91	0.81	0.71	0.81	0.85	0.68	
	CI (95%)	0.22	0.20	0.17	0.20	0.21	0.17	
When I see my GP I feel confident to discuss options for treating my asthma.	*n*	58	58	58	58	58	58	0.811
	Mean	5.21	5.45	5.10	5.40	-0.10	-0.05	
	SD	1.42	1.22	1.52	1.18	1.29	1.02	
	CI (95%)	0.37	0.31	0.39	0.30	0.33	0.26	
When I see my GP I feel confident to ask any questions I may have about my asthma.	*n*	62	62	62	62	62	62	0.013
	Mean	5.35	5.68	5.60	5.56	0.24	-0.11	
	SD	1.09	0.95	0.90	0.95	0.90	0.66	
	CI (95%)	0.27	0.24	0.22	0.24	0.22	0.16	
When I see my GP I feel as involved as I want to be in decisions about my care.	*n*	60	60	60	60	60	60	0.070
	Mean	5.25	5.57	5.40	5.42	0.15	-0.15	
	SD	1.28	0.93	1.25	1.14	0.99	0.80	
	CI (95%)	0.32	0.23	0.32	0.29	0.25	0.20	

** Any value < 0.05 is statistically significant to the 5% level*

These findings are supported by indicative data from a further question in the follow-up questionnaire. This asked respondents to indicate their level of agreement with statements comparing their current attitude with "6 months ago" using a five point scale (5=strongly agree, 1=strongly disagree). The statement "I feel more confident about

[29] National Expert Patients Programme Internal Monitoring (2005). Department of Health, England.

managing my asthma" had a mean agreement score of 3.62 in the intervention group compared to 3.59 in the control group (although this was non-significant to the 5% level).

Two measures of attitudes towards asthma medication also showed significant change in the intervention group compared to the control group. These suggest a growing realisation of other things that can be done apart from taking medicines to take care of their condition, and also reduced concern about the side effects of medication (Table 6.5).

The comparative statement "I use more medication for my asthma" compared with 6 months ago received slightly more agreement from intervention group respondents than from control group respondents, but this was not statistically significant. There was also more agreement with this statement in the intervention group when responses were analysed for the subgroup who attended the EPP course (n=26 who completed this part of the questionnaire, paired with 26 control group respondents), but again this difference versus the control group was not significant.

When asked specifically about the average number of times per day different medication was used, the intervention group reported slightly less use of both reliever and preventer medication at follow-up compared to baseline. However, this change was non-significant in comparison with the control group. The findings on medication usage are therefore inconclusive.

Table 6.5: Change in Attitudes to Asthma Medication
(1=never; 6=all the time)

		Baseline		Follow-up		Change		P-Value change (Int vs ctl)*
		Intervention	Control	Intervention	Control	Intervention	Control	
I take my asthma medication as prescribed.	*n*	71	71	71	71	71	71	0.483
	Mean	5.62	5.25	5.70	5.23	0.08	-0.03	
	SD	0.78	1.12	0.68	1.17	0.69	1.16	
	CI (95%)	0.18	0.26	0.16	0.27	0.16	0.27	
I don't like the effect my asthma medication has on me.	*n*	60	60	60	60	60	60	0.571
	Mean	2.15	1.93	2.12	1.78	-0.03	-0.15	
	SD	1.45	1.31	1.32	0.88	1.16	1.09	
	CI (95%)	0.37	0.33	0.33	0.22	0.29	0.27	
I can do things other than taking medication to manage my asthma.	*n*	58	58	58	58	58	58	0.023
	Mean	1.97	2.47	2.62	2.47	0.66	0.00	
	SD	1.38	1.50	1.44	1.39	1.48	1.58	
	CI (95%)	0.35	0.39	0.37	0.36	0.38	0.41	
I worry about the side effects that I might have from the medication.	*n*	64	64	64	64	64	64	0.013
	Mean	2.56	2.00	2.22	2.20	-0.34	0.20	
	SD	1.53	1.37	1.24	1.38	1.28	1.17	
	CI (95%)	0.38	0.34	0.30	0.34	0.31	0.29	
I sometimes adjust my medication to suit my symptoms.	*n*	70	70	70	70	70	70	0.537
	Mean	3.29	3.53	3.51	3.57	0.23	0.04	
	SD	1.50	1.35	1.41	1.57	1.74	1.81	
	CI (95%)	0.35	0.32	0.33	0.37	0.41	0.42	

** Any value < 0.05 is statistically significant to the 5% level*

None of the other attitude statements comparing with "6 months ago" showed a significant difference between the EPP subgroup and their matched controls. The key changes were therefore those reported for the full intervention sample in Table 6.5.

6.5.3 Use of health services

The mean number of GP visits in the last 3 months was slightly higher in the intervention group (from 0.92 to 1.30) and slightly lower in the control group (p=0.045). This finding is supported by data on the comparative statement "I need to see the GP or practice nurse less often than before" which received more agreement from the control group than from the intervention group (although this difference was not significant).

It appears that more intervention respondents felt that something had changed with their asthma compared to those in the control group (p=0.005 for the comparative question "nothing has changed with my asthma"), and this may explain the higher rate of GP consultation. In the subgroup who attended the 7-week EPP course and also answered this question (n=26), there was a similar difference in relation to "nothing has changed with my asthma" (p=0.006), suggesting more change in the condition amongst this intervention subgroup.

There were no significant differences on any other measure of health service use relating to asthma (A&E or outpatient visits, hospital admissions, use of NHS Direct, use of Walk-in Centres, or use of complementary medicine specialists). No respondents in either the intervention or control sample had used NHS Direct regarding their asthma at baseline, and only one call had been made by a respondent in the intervention group at follow-up. No-one had used an NHS walk-in centre at any point (although this definition may not have been associated with the Minor Injuries Unit in Ilkeston).

Analysis was also undertaken on the intervention sample subgroup who attended the EPP course, whether or not they also attended a half day session (n=28 respondents to this section of the questionnaire). There were no significant differences in their use of health services versus the control group, at follow-up compared to baseline, although there was again a slight but non-significant increase in the mean number of GP visits (from 1.25 to 1.50) in the EPP group.

6.5.4 Response to the EPP programme and half day events

The community survey by market research company 2Europe found that, amongst the 3% of the sample of 540 respondents who were aware of any self care programmes being promoted locally (n=18), 39% recalled "something to do with asthma". This, along with "something to do with heart disease", was the highest level of prompted recall of any of the options given.

It proved more difficult than anticipated to recruit participants to the EPP courses. This in part reflected the logistical difficulties in organising the courses at times convenient to patients, and the time commitment required from patients to attend such a course. These problems were not unique to Erewash. A national study of recruitment to EPP courses found that only a quarter of PCTs had good rates of recruitment at the time the JUSC EPP

courses were being organised[30]. Problems with recruitment were associated with a reliance on a paper-based strategy and poorly developed links to the broader community and health professionals

Three half day asthma-specific taster sessions were therefore organised in Erewash, to provide both a separate option for some patients and to raise awareness of the EPP courses themselves. Alongside promotion of these events the PCT asked respondents if they had signed up for an EPP course, and if not why not. 103 responses were received:

- 51% said they felt they could take care of their asthma well and would not benefit from an EPP course
- 29% said the day or time of the course was not suitable (often because they could not get time off work)
- 23% said they would not have been able to attend all the sessions

At the single half days sessions themselves a brief evaluation questionnaire was used by the PCT. All 72 respondents to this questionnaire rated the session as "good" or "excellent" and 40 (56%) said they would now be likely to attend an EPP course.

Those who participated in the EPP (n=30) were asked to complete a pre-course questionnaire at the start of the final (seventh) session and a post-course questionnaire at the end of the final session.

21 participants completed both the pre and post-course questionnaires. A profile of this subgroup is given in Table 6.6 below.

Table 6.6: EPP - Questionnaire Sample Profile

Profile of respondents completing pre/post-course questionnaire for EPP	EPP Intervention
Number of respondents	21
Gender (%)	
Male	8 (38.10%)
Female	13 (61.90%)
Mean age (SD)	53.57 (SD 15.4)
Have a child with asthma (%)	3 (14.29%)
Do not own their accommodation (%)	3 (14.29%)
Not in paid employment (%)	13 (61.90%)

Based on a four point scale (1="strongly disagree", 4="strongly agree"), there were no significant differences between the pre and post-course mean scores for knowledge of how to use a peak flow meter, knowledge of how to manage an asthma attack, knowledge of asthma triggers, or confidence in asking a nurse or doctor about tests or in what to do if

[30] Kennedy A, Rogers A, Gately C. (2005) Assessing the Introduction of the Expert Patients Programme into the NHS: a realistic evaluation of recruitment to a national lay-led self-care initiative. *Primary Health Care Research & Development*; 6:137-148

the asthma gets worse. But it is not possible to make any definitive conclusions based on data from only 21 participants.

Many of the questions in the post-course questionnaire (used with permission from Asthma UK) concerned experience of the course itself, and comparisons between pre and post-course were only possible for questions that were identical at both time points.

There were very high levels of agreement with the following statements in the post-course questionnaire:

> *"I feel that I know more about my treatments and medications after completing this course"*: mean score 3.67 (SD 0.48)
>
> *"I know what to expect from the health service (doctors, nurses, clinics) in managing my asthma"*: mean score 3.00 (SD 0.71)
>
> *"I feel confident that I would be able to speak to my nurse or doctor about the Stepwise programme"*: mean score of 3.38 (SD 0.74)
>
> *"After attending the course, I feel I know more about how to reduce my symptoms"*: mean score 3.32 (SD 0.48)

This contrasts with some pre-course statements which showed lower levels of agreement:

> *"I feel I know how to reduce my symptoms"*: mean score 2.90 (SD 0.55)
>
> *"I feel able to identify my asthma triggers"*: mean score 2.95 (SD 0.62)
>
> *"I know about what I can do to avoid my triggers"*: mean score 2.95 (SD 0.62)

Following the course, many respondents indicated in the open-ended parts of the questionnaire that they would now talk more with their nurse or GP, for example regarding peak flow meters, x-rays or blood tests.

One respondent commented, after completing the EPP course:

> *"I've learned more in the past few weeks than I have in the last fifteen years"*

An EPP course reunion was held in April 2006. Most people were very positive about how they had benefited from the course and examples were given of how participants had gained confidence to do things they had thought they were unable to do prior to attending the course. Two people were interested in setting up a local asthma support group

The reunion also came up with some specific suggestions for the PCT:

- A session including family / carers / support networks, or a separate event like the ½ day events.
- A whole evening session with an asthma nurse.

- The PCT should inform nurses and GPs about the course and it needs more publicity in surgeries, community & the media
- More training in asthma is needed for nurses and GPs.

The half day events as well as the EPP generated a number of letters to the PCT which included comments such as the following:

"This was the best thing I could have done to help me cope with my Asthma"

"I found the course extremely enjoyable and beneficial to my condition. I learnt new things such as breathing exercises which I found did improve my symptoms"

"I find this an excellent course…the setting of an action plan for each person…encourages us to be more active"

"We have worked very well as a group… we have learnt different things from each other"

6.6 Quality of Life

Two sections of the postal survey questionnaire comprised the Mini Asthma Quality of Life Questionnaire (MiniAQLQ) developed by Prof Elizabeth Juniper. The MiniAQLQ has been developed for, amongst other things, use in larger surveys requiring patient self completion and has been well validated in previous research[31].

For scoring purposes the 15 questions of the MiniAQLQ are divided into four domains:

Symptoms
Activity Limitations
Emotional Function
Environmental Stimuli

All questions (items) comprise seven point scales (1=all of the time, 7=none of the time) and are equally weighted. The results can be expressed as the mean score per item or per domain, with higher scores reflecting better quality of life. Results for domains with different numbers of items are expressed in the same way for each domain. Overall quality of life is estimated from the mean score of all the items.

To enable analysis, the sample used has to consist of respondents who have answered all the 15 questions. For the JUSC sample, 54 intervention group respondents met this criterion and were matched with equivalent control group respondents.

[31] Juniper EF et al. (1999) Development and Validation of the Mini Asthma Quality of Life Questionnaire. *European Respiratory Journal*; 14: 32-38

Table 6.7 shows the mean scores for each domain and overall at baseline and follow-up. The minimal important change has been found in previous research[32] to be 0.5, but none of the changes reported in the JUSC survey reached this level.

Table 6.7: Mean Quality of Life Scores – Intervention vs Control

Quality of Life (n=54) Based on MiniAQLQ	Baseline		Follow-up		Change*	
	Intervention	Control	Intervention	Control	Intervention	Control
Symptoms	4.53	4.66	4.60	4.80	0.07	0.14
Activity limitations	5.11	5.23	5.09	5.32	-0.02	0.08
Emotional function	4.57	4.92	4.75	4.88	0.18	-0.04
Environmental stimuli	3.73	4.30	3.83	4.31	0.10	0.01
Overall quality of life	4.53	4.79	4.61	4.85	0.08	0.06

** Any change of a magnitude greater than 0.5 is considered to be clinically important*

In order to explore possible changes at the individual respondent level, the absolute number of patients who reported a change of >0.5 was also analysed. Table 6.8 shows that more intervention group respondents reported an improvement in emotional function and environmental stimuli (compared to the control group), but these differences are not statistically significant.

Table 6.8: Respondents Reporting Changes in Quality of Life

Number of patients who experienced a clinically important** change in their quality of life (n=54)		Difference		P-Value (Int vs ctl)*
		Intervention	Control	
Symptoms	Improvement	14	16	0.910
	No Change	25	24	
	Decline	15	14	
Activity limitations	Improvement	17	16	0.833
	No Change	20	23	
	Decline	17	15	
Emotional function	Improvement	16	14	0.909
	No Change	25	26	
	Decline	13	14	
Environmental stimuli	Improvement	19	16	0.810
	No Change	22	23	
	Decline	13	15	
Overall quality of life	Improvement	15	13	0.904
	No Change	27	28	
	Decline	12	13	

** Any value < 0.05 is statistically significant to the 5% level*

*** Any change of a magnitude greater than 0.5 is considered to be clinically important*

Comparison was also undertaken between the subgroup who attended the EPP course and those who only attended a half day session. Table 6.9 indicates no consistent pattern in this comparison, with the EPP group showing slight improvement in symptoms and

[32] Juniper EF et al. (1994) Determining a minimal important change in a disease-specific quality of life questionnaire. *Journal of Clinical Epidemiology*: 47(1): 81-87

emotional function and the half day group showing very slight improvement in activity limitations and environmental stimuli. Overall quality of life improved in both groups (as it did in the control group) but none of these changes were significant.

Table 6.9: Mean Quality of Life Scores – EPP vs Half Day

EPP vs half-day course, quality of life (n=54) Based on MiniAQLQ	Baseline		Follow-up		Change*	
	EPP	Half-day	EPP	Half-day	EPP	Half-day
Symptoms	4.50	4.55	4.75	4.55	0.25	-0.01
Activity limitations	5.43	4.98	5.25	5.02	-0.17	0.04
Emotional function	4.59	4.75	5.00	4.71	0.41	-0.04
Environmental stimuli	4.27	3.68	4.16	3.95	-0.11	0.27
Overall quality of life	4.71	4.53	4.82	4.59	0.10	0.06

** Any change of a magnitude greater than 0.5 is considered to be clinically important*
Numbers are rounded to two decimal places

While it might not be expected that a single half day taster session would have a significant impact on self care of asthma, it was hypothesised that an EPP course might do so. Data from each of the 15 individual questions/items of the MiniAQLQ were therefore analysed for the EPP group and the half day group separately. The EPP group was small so the power to detect changes in any quantitative health outcome was low.

No significant changes were found between baseline and follow-up, or for the whole intervention sample combined. Most mean scores on individual questions were between 3 ("a good bit of the time") and 4 ("some of the time"). The only mean scores <3 (indicating lower quality of life) were for the following items, in both the EPP group and the half day group:

During the last 2 weeks were you limited doing SOCIAL ACTIVITIES

During the last 2 weeks were you limited doing WORK RELATED ACTIVITIES

The control group as a whole had slightly lower scores for both these items, but not significantly so, compared to the intervention group.

As indicated earlier, there was a decline in both the intervention and control groups on three symptom measures (breathlessness, wheezing and chest heaviness/tightness) and a decline in the control group on coughing (versus an increase in the intervention group), but none of these differences were statistically significant.

Overall, because there were 30 participants (compared with the target of 100 for the EPP course) and the time gap between baseline and follow-up was much shorter than originally planned, it is not possible to make any quantitatively definitive conclusions about the effectiveness of the course. Qualitative findings of JUSC however strongly suggest that EPP courses can have a positive impact on participants.

7. EVALUATION OF INTERVENTIONS IN MINOR AILMENTS

7.1 Key Outcome Measures

- Participation levels in the Pharmacy First minor ailments scheme
- Increased use of pharmacies and NHS Direct for advice
- Reduced rates of GP consultation for children's minor ailments, prescriptions for specific minor ailments, and general prescribing indicators including head lice treatments and antibiotics
- Awareness levels of self care options and likely future actions by mothers.

7.2 Summary & Implications

We compared those who participated in Pharmacy First against controls who did not.
The following were the findings against our key outcome measures:

- Approximately one in five eligible families took up Pharmacy First; users reported a positive experience and will continue to use the scheme
- There was no significant difference between the intervention and control groups in numbers of GP consultations following registration. There was a small increase in practice nurse consultations in the intervention group
- Attitudes towards consulting a pharmacist for a child's minor ailment were very positive amongst both the intervention and the control groups; and, except for younger mothers, respondents in both groups were more likely to do so in the future
- Trends towards use of self care for several childhood minor ailments were slightly greater in the Pharmacy First group
- Awareness of the JUSC programme was higher amongst mothers of any age than amongst the general population.

The key implications are:

- Pharmacy First was well accepted as a way of accessing primary care
- Because it was not possible to directly link GP consultations and Pharmacy First usage, and the time-frame for follow-up was too short to reach "steady state"[33], it is not possible to draw conclusions about workload
- Pharmacy First showed the potential for changing the perceived roles of health professionals; it did not, however, provide strong evidence of making participants more self-sufficient and confident in self care
- In the future, attention should focus on ensuring that pharmacy minor ailment schemes do not simply transfer dependency from one professional to another. Pharmacists' skills in supporting self care can be further developed as part of this work
- The take-up of self care for minor ailments is crucially dependent on community-wide publicity and the engagement of health professionals and other key influencers in the community

[33] Schafheutle E et al (*op cit* p16) report that registrations in the Scottish pilot schemes were still growing at 12 months.

7.3 Activity Overview

As outlined in chapters 2 and 3, the minor ailments intervention was as follows:

- Promotion and registration of children aged 3 months–12 years into Pharmacy First. It should be noted that over 70% of the mothers/carers who registered their children did so before the start of the JUSC programme in February 2005 (see Figure 7.1)
- Community-wide distribution of information booklets and leaflets including "Better Health at Home and at Work", "Caring for Kids" and material relating to four seasonal campaigns (summer ailments, hay fever, winter ailments and back to school)
- PR activity supporting the seasonal campaigns and minor ailments promotion generally, which generated local press coverage

It was clearly not possible to target the distribution of minor ailments information and the seasonal campaigns exclusively at intervention respondents (ie. children and mothers/carers participating in Pharmacy First). This means the control group was also exposed to these interventions; the comparison between intervention and control groups is therefore not a pure one because both groups were exposed to the community wide promotional activity.

As outlined in Chapter 4, the evaluation comprised:

- Postal survey of Pharmacy First mothers/carers and controls at baseline and follow-up
- Consultation and prescribing record audit of Pharmacy First mothers/carers and controls at follow-up
- Focus groups of Pharmacy First mothers/carers and controls at follow-up

7.4 Sample Profile & Baseline Characteristics

The intervention sample for the Minor Ailments module was drawn from the Ilkeston area of the PCT where the Pharmacy First scheme was already in place at the start of the JUSC programme. The control sample was taken from the Long Eaton area where Pharmacy First was not rolled out until Autumn 2005.

In each case sampling took place via GP practices agreeing to participate in the JUSC survey. The intervention group was sampled from practices participating in Pharmacy First; the control group was sampled from practices not participating in Pharmacy First at baseline (ie. Long Eaton practices).

The baseline survey generated 121 intervention respondents and 215 control respondents. The intervention respondents represent mothers or carers of children aged 3 months to 12 years registered under Pharmacy First, regardless of how many children each

mother/carer had registered. The PCT estimates that a total of 444 families had Pharmacy First available to them in Ilkeston at the start of the JUSC programme and a further 156 families had it available in Long Eaton from the start of October 2005. The overall response rate for mothers/carers therefore equates to 121/(444+156) = 20% of the total population of families who had Pharmacy First available.

Outline profile details for the intervention and control groups are given in Table 7.1 below.

Table 7.1: Minor Ailments Survey - Baseline Sample Profile

Baseline profile - all respondents	Intervention	Control
Number of respondents	121	215
Mean age	33.2 (SD 5.9)	35.6 (SD 6.0)
Mean child age	6.8 (SD 4.8)	8.0 (SD 4.7)
Do not own their accommodation (%)	30 (24.79%)	33 (15.35%)
Full time parent (%)	55 (45.45%)	69 (32.09%)
Not in paid employment (%)	42 (34.71%)	57 (26.51%)

The follow-up survey generated 92 intervention respondents (76% response) and 149 control respondents (69% response). The control sample was matched to the intervention sample on the variables shown in Table 7.1, resulting in the profile given in Table 7.2. These were the samples used for analysis of the change between baseline and follow-up.

After matching for age and housing status (the latter as a proxy for socio-economic status), the intervention and control groups were very similar, including employment status. A slightly higher proportion of the intervention (Pharmacy First) group had three or more children (18%) and classed themselves as a full time parent (46%).

The majority of respondents in both groups said they can generally take care of minor ailments with the advice of a pharmacist. For children's illnesses in the last 6 months, both groups predominantly treated the symptoms themselves. However, a higher proportion of the intervention group (93%) sought advice from a pharmacist (79% in the control group) and >89% in each group bought OTC medications in the last 6 months.

A higher proportion of the intervention group had visited the GP (88%) or A&E (42%) with their child in the last 6 months.

There was strong agreement between the groups that certain ailments require GP advice, but most were also happy to see a pharmacist for most minor ailments. The main reason for seeing a GP was if they thought antibiotics were needed.

The intervention group were slightly more likely (compared to the control group) to seek help from a pharmacist for a child with:

- Cough

- Head lice
- Constipation
- Hay fever
- Mild rash
- Insect bites/stings
- Athletes foot
- Worms (although GP help was often cited for this condition)

7.5 Comparison of Baseline & Follow-up Measures

7.5.1 Follow-up sample profile

During the course of the JUSC programme some baseline respondents in the Long Eaton control group transferred to the intervention group as Pharmacy First was rolled out in that area. As the survey questionnaires were the same for both groups, this re-categorisation did not impact on the data analysis. However, it did mean that Long Eaton intervention group respondents participated in Pharmacy First for a shorter period of time than those in Ilkeston (see Section 7.5.4 for details on the pattern of Pharmacy First registrations).

The profile of the follow-up sample for the postal survey is given in Table 7.2.

Table 7.2: Minor Ailments Survey - Follow-up Sample Profile

Follow-up profile - paired respondents	Intervention	Control
Number of respondents	92	92
Mean age	34.62 (SD 5.6)	34.82 (SD 5.5)
Mean child age	6.5 (SD 4.1)	7.3 (SD 4.0)
Do not own their accommodation (%)	17 (18.48%)	20 (21.74%)
Full time parent (%)	37 (40.22%)	42 (45.65%)
Not in paid employment (%)	28 (30.43%)	25 (27.17%)

Two subgroups were also identified for follow-up. The first of these were intervention and control group respondents whose registered children had GP and Pharmacy First records which could be audited. The profile of this subgroup is given in Table 7.3.

The intervention and control groups in the record audit were well matched, although there was a higher proportion of the control group in full or part time employment.

Table 7.3: Minor Ailments Record Audit – Sample Profile

	Intervention	Control
Parents	83	95
Parent median age	33	34
Parent mean age (SD)	33.33 (5.44)	33.49 (5.77)
Own property (% of parents)	71.08%	71.58%
Full-time paid employment (% of parents)	20.48%	22.11%
Part-time paid employment (% of parents)	43.37%	49.47%
Full-time parent (% of parents)	48.19%	31.58%
Children	172	172
Median children per parent	2	2
Mean children per parent (SD)	2.07 (1.02)	1.81 (0.83)
Mean child age years (SD)	6.2 (4.28)	6.61 (3.47)
Records in GP audit	95	115
Median records per parent	1	1
Mean records per parent (SD)	1.14 (0.42)	1.21 (0.46)

The second subgroup was mothers who agreed to participate in focus group discussions at the end of March 2006. Two focus groups were held with intervention group participants in Ilkeston (n=13), and two with control group respondents in Long Eaton (n=5). The control group participants were more affluent (reflected in the fact that they all owned their own accommodation) and only one of them was not in paid employment. The profile of focus group participants is given in Table 7.4.

Table 7.4: Minor Ailments Focus Groups – Sample Profile

	Intervention	Control
Number of respondents	13	5
Mean age	35.23	42.00
Mean child age	6.42	8.80
Do not own their accommodation (%)	38.46%	0.00%
Full time parent (%)	53.85%	20.00%
Not in paid employment (%)	61.54%	20.00%

7.5.2 Attitudes towards care of minor ailments

General attitudes towards the care of minor ailments were assessed in part by the postal survey. When respondents were asked to tick one of three general statements, the most common agreement in both the intervention and control groups was with "*In general I believe I can manage most of my child's health and minor medical problems with advice from a pharmacist*".

Although the intervention group reported higher levels of agreement at both baseline and follow-up, the change in this group compared to the control group was not significant (Table 7.5)

Table 7.5: General Attitudes to Minor Ailment Management

		Baseline		Follow-up		Change		P-value change (Int vs ctl)*
		Intervention	Control	Intervention	Control	Intervention	Control	
In general, I believe it is always best to get the opinion of a doctor when my child is ill, even with minor ailments.	*pop*	73	73	73	73	73	73	0.201
	n	7	8	1	5	-6	-3	
	%	9.59%	10.96%	1.37%	6.85%	-8.22%	-4.11%	
In general, I believe I can manage most of my child's health and minor medical problems with advice from a pharmacist.	*pop*	73	73	73	73	73	73	0.490
	n	46	42	50	37	4	-5	
	%	63.01%	57.53%	68.49%	50.68%	5.48%	-6.85%	
In general, I believe I can manage most of my child's health and minor medical problems myself.	*pop*	73	73	73	73	73	73	0.623
	n	20	23	22	31	2	8	
	%	27.40%	31.51%	30.14%	42.47%	2.74%	10.96%	

** Any value < 0.05 is statistically significant to the 5% level*

Five point scales were also used in the postal survey to assess respondents' level of agreement with a number of statements relating to the management of minor ailments (1= strongly disagree, 5= strongly agree). As at baseline, the highest levels of agreement (mean >4) in both the intervention and control groups were with the following statements:

- *Pharmacists are qualified to give advice and treatment on most minor ailments* (the level of agreement with this statement increased slightly in the intervention group between baseline and follow-up)
- *The main reason I would see the GP about my child's illness would be if I thought antibiotics were needed*
- *There are certain ailments where only a doctor can tell you what treatment is needed*

By contrast, the lowest levels of agreement (mean <2.1) were with the following statements:

- *I would not be happy to see a pharmacist for advice about my child's illness*
- *Pharmacists cannot give independent advice because they make their living from selling medicines*

The level of agreement with these statements was lower in the intervention group than the control group at both baseline and follow-up, and the level of agreement in the intervention group declined between the two time points (although these differences and declines were not statistically significant).

7.5.3 Treatment approaches

The survey data showed no significant differences between the intervention and control groups in terms of changes (follow-up versus baseline) in their actions to treat children's minor ailments.

There was also no difference between the intervention and control groups in terms of change in where they would first seek help for any of the 21 minor childhood ailments listed.

The analysis for this part of the survey data was based on matched pairs (intervention and control) where both mothers/carers had a child who had been ill in the last 6 months at both baseline and follow-up. This strict definition of the subgroup who had experienced a child's illness was necessary to avoid responses from mothers/carers who had done nothing in one of the periods simply because their child had not been ill. Responses to the questions on actions taken if their child had been ill ranged from n=32 to n=38.

However, analysis of the cross-sectional differences in use of GPs, pharmacists and self treatment at baseline and follow-up separately reveals some significance (based on a chi-squared test). Intervention group respondents would first seek help from different sources to control group respondents for the following childhood conditions:

- **Earache** and **Flu:** Intervention group respondents were more likely to see the GP or pharmacist and less likely to treat it themselves without advice

- **Temperature, Mild Rash, Hay Fever, Insect Bites/stings, Sticky Eyes** and **Worms:** Intervention group respondents were more likely to see the pharmacist and less likely to see the GP or treat it themselves

- **Colic:** Intervention group respondents were more likely to see the pharmacist (and less likely to see the Health Visitor, although this was not included in the test of significance)

All these differences were significant at baseline but not at follow-up.

Response numbers for NHS Direct were too low to enable robust analysis. No responses of greater than nine were seen in either group at baseline or follow-up, and only one condition (temperature) had any responses greater than five.

Although there were no statistically significant changes between baseline and follow-up in the intervention group, there are some indicative trends regarding use of the GP, pharmacist or self treatment. Based on a change of ten percentage points or more (in the proportion of respondents citing this as their first source of advice), the intervention group at follow-up indicated they had become:

- less likely to see the GP and more likely to self treat for **Earache**

- less likely to see the GP for **Eczema**
- less likely to see the pharmacist and more likely to self treat for a **Cough, Mild Rash, Insect Bites/stings** or **Teething**
- more likely to self treat for a **Nappy Rash**

The data indicating these changes are shown in the "Change" Intervention column in Table 7.6.

Table 7.6: First Sources of Help for Minor Ailments

Where would you first seek help for a child with…			Baseline		Follow-up		Change**		P-value change (Int vs ctl)*
			Intervention	Control	Intervention	Control	Intervention	Control	
Earache (Total Responses: 84)	GP	*n*	47	43	35	41	-12	-2	0.428
		%	55.95%	51.19%	41.67%	48.81%	-14.29%	-2.38%	
	Pharmacist	*n*	21	11	24	14	3	3	0.830
		%	25.00%	13.10%	28.57%	16.67%	3.57%	3.57%	
	Self-Treatment	*n*	13	24	22	28	9	4	0.404
		%	15.48%	28.57%	26.19%	33.33%	10.71%	4.76%	
P-Value (int vs ctl)*			**0.038**		**0.149**		**0.118**	**0.756**	
Cough (Total Responses: 87)	GP	*n*	4	1	2	0	-2	-1	0.495
		%	4.60%	1.15%	2.30%	0.00%	-2.30%	-1.15%	
	Pharmacist	*n*	39	30	28	32	-11	2	0.264
		%	44.83%	34.48%	32.18%	36.78%	-12.64%	2.30%	
	Self-Treatment	*n*	44	55	57	55	13	0	0.349
		%	50.57%	63.22%	65.52%	63.22%	14.94%	0.00%	
P-Value (int vs ctl)*			**0.123**		**0.316**		**0.126**	**0.589**	
Mild rash (Total Responses: 84)	GP	*n*	11	16	10	13	-1	-3	0.845
		%	13.10%	19.05%	11.90%	15.48%	-1.19%	-3.57%	
	Pharmacist	*n*	42	24	30	32	-12	8	0.082
		%	50.00%	28.57%	35.71%	38.10%	-14.29%	9.52%	
	Self-Treatment	*n*	24	34	40	28	16	-6	0.051
		%	28.57%	40.48%	47.62%	33.33%	19.05%	-7.14%	
P-Value (int vs ctl)*			**0.023**		**0.323**		**0.050**	**0.363**	
Nappy rash (Total Responses: 84)	GP	*n*	0	2	0	2	0	0	Unknown
		%	0.00%	2.38%	0.00%	2.38%	0.00%	0.00%	
	Pharmacist	*n*	18	5	13	8	-5	3	0.235
		%	21.43%	5.95%	15.48%	9.52%	-5.95%	3.57%	
	Self-Treatment	*n*	59	67	68	68	9	1	0.607
		%	70.24%	79.76%	80.95%	80.95%	10.71%	1.19%	
P-Value (int vs ctl)*			**0.007**		**0.209**		**Unknown**	**0.743**	
Eczema (Total Responses: 84)	GP	*n*	46	54	37	52	-9	-2	0.540
		%	54.76%	64.29%	44.05%	61.90%	-10.71%	-2.38%	
	Pharmacist	*n*	23	15	26	17	3	2	0.996
		%	27.38%	17.86%	30.95%	20.24%	3.57%	2.38%	
	Self-Treatment	*n*	11	13	17	13	6	0	0.429
		%	13.10%	15.48%	20.24%	15.48%	7.14%	0.00%	
P-Value (int vs ctl)*			**0.291**		**0.085**		**0.294**	**0.922**	
Insect bites/stings (Total Responses: 84)	GP	*n*	5	6	3	2	-2	-4	0.590
		%	5.95%	7.14%	3.57%	2.38%	-2.38%	-4.76%	
	Pharmacist	*n*	50	30	37	36	-13	6	0.141
		%	59.52%	35.71%	44.05%	42.86%	-15.48%	7.14%	
	Self-Treatment	*n*	29	47	39	43	10	-4	0.233
		%	34.52%	55.95%	46.43%	51.19%	11.90%	-4.76%	
P-Value (int vs ctl)*			**0.009**		**0.825**		**0.152**	**0.259**	
Teething (Total Responses: 84)	GP	*n*	0	2	0	0	0	-2	Unknown
		%	0.00%	2.38%	0.00%	0.00%	0.00%	-2.38%	
	Pharmacist	*n*	26	7	14	9	-12	2	0.144
		%	30.95%	8.33%	16.67%	10.71%	-14.29%	2.38%	
	Self-Treatment	*n*	52	67	65	69	13	2	0.444
		%	61.90%	79.76%	77.38%	82.14%	15.48%	2.38%	
P-Value (int vs ctl)*			**0.001**		**Unknown**		**Unknown**	**0.324**	

** Any value < 0.05 is statistically significant to the 5% level*
*** Circled numbers indicate >10 % point change*

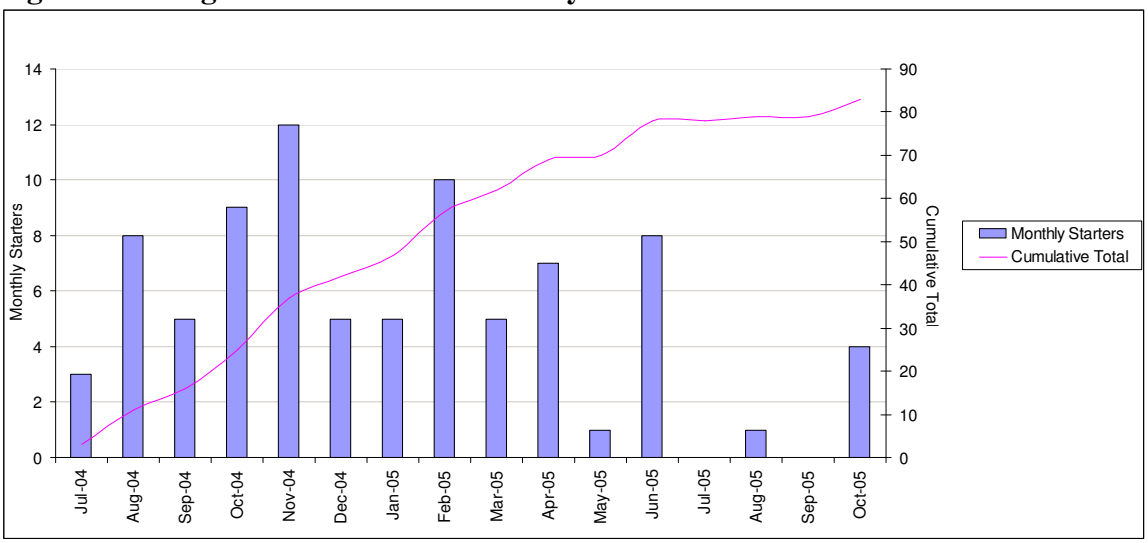
7.5.4 Response to the Pharmacy First programme

Programme take-up

Registration under the Pharmacy First programme was oriented towards the period before the initiation of the JUSC programme. Figure 7.1 shows that the majority of registrations occurred prior to April 2005 when the first baseline survey questionnaires were issued. (Figure 7.1 is based on mother/carer records but there were no instances of children of the same mother being registered at different dates)

This pattern of registration may have affected the JUSC findings if mothers had already adopted "Pharmacy First behaviour" by the time of the baseline survey; positive change at follow-up might not be expected from those respondents.

Figure 7.1: Registrations under Pharmacy First



The PCT's records indicate that, over the period April 2005-March 2006 (ie. approximately the period of the JUSC evaluation), a total of 1,384 pharmacy consultations were held under the Pharmacy First programme.

The programme was intended primarily for people who are exempt from the prescription charge. However, it could also be accessed by people who are not exempt from the prescription charge, mainly to gain information and advice about symptoms and medicines without the need to see the GP. Ninety six percent of consultations under the scheme resulted in medication being provided (the most common being paracetamol). However, 99% of consultations involved no collection of a prescription charge, reflecting the high use of the scheme for children.

Sixty three percent of Pharmacy First consultations were for children aged 15 years or younger (Table 7.7) and the most common condition was headlice (Table 7.8); this is

consistent with the findings of the Scottish pilot minor ailment scheme[34]. Table 7.8 shows the breakdown by first condition in each consultation (since some consultations covered more than one condition).

Table 7.7: Pharmacy First Consultations by Age of Patient (April 2005-March2006)

Age of patient	n	% of total
<4 years	327	23.6%
4 to 5 years	85	6.1%
5 to 6 years	63	4.6%
6 to 10 years	262	18.9%
10 to 15 years	136	9.8%
>15 years	511	36.9%
Total	**1384**	**100.0%**

Table 7.8: Pharmacy First Consultations by Condition (April 2005-March 2006)

First condition	n	% of total
Bites and Stings	393	28.4%
Conjunctivitis	198	14.3%
Constipation	113	8.2%
Diarrhoea	94	6.8%
Dry skin	89	6.4%
Earwax	89	6.4%
Hayfever	44	3.2%
Headlice	39	2.8%
Headache	36	2.6%
Indigestion, tum ache, heartburn	34	2.5%
Nappy rash	34	2.5%
Oral thrush	33	2.4%
Scabies	32	2.3%
Sore Throat	31	2.2%
Teething	26	1.9%
Temperature	24	1.7%
Threadworm	22	1.6%
Tinea Infection	17	1.2%
Toothache	16	1.2%
Urinary Tract Infection	14	1.0%
Vaginal Thrush	5	0.4%
Unrecorded	1	0.1%
Total	**1384**	**100.0%**

Record audit

The audit of GP and Pharmacy First records for the intervention group compared the 6 months following registration (the "trial" period") with the equivalent 6 months in the

[34] Schafheutle EI, Noyce PR, Sheehy C, Jones L. (2003) Direct Supply of Medicines in Scotland: Evaluation of a Pilot Scheme; Health & Community Care Research Programme, Scottish Executive Social Research: Research Findings No. 29

previous year. For the control group the comparison was between 1st June-30th November 2005 and 1st June-30th November 2004. This means that the periods used to evaluate change were not exactly the same for all respondents in both groups, but the data are normalised for seasonality.

The audit found that GP consultations were slightly higher in both groups in the follow-up period, but the difference in the increases was not significant. Practice nurse consultations and prescriptions for oral antibiotics increased significantly in the intervention group versus a decline in the control group (p=0.007 respectively). (Table 7.7) In relation to antibiotic prescriptions however, it must be noted that due to inconsistencies in record keeping it may have been difficult for the auditor to have known what the prescriptions were for and in one case the prescription was for 'chest infection' a condition not included in Pharmacy First.

Table 7.9: Minor Ailments Record Audit

	Intervention			Control			P-Value change (Int vs ctl)*
	Trial Period	Previous Year	Absolute Change	Trial Period	Previous Year	Absolute Change	
GP consultations	37	30	7	37	33	4	0.710
Mean consultations per parent	0.45	0.36	0.08	0.39	0.35	0.04	
Mean consultations per GP audit record	0.39	0.32	0.07	0.32	0.29	0.03	
Practice nurse consultations	11	1	10	0	2	-2	0.001
Mean consultations per parent	0.13	0.01	0.12	0.00	0.02	-0.02	
Mean consultations per GP audit record	0.12	0.01	0.11	0.00	0.02	-0.02	
Telephone consultations	3	5	-2	1	0	1	0.247
Mean consultations per parent	0.04	0.06	-0.02	0.01	0.00	0.01	
Mean consultations per GP audit record	0.03	0.05	-0.02	0.01	0.00	0.01	
Headlice prescriptions	0	2	-2	0	0	0	0.130
Mean prescriptions per parent	0.00	0.02	-0.02	0.00	0.00	0.00	
Mean prescriptions per GP audit record	0.00	0.02	-0.02	0.00	0.00	0.00	
Oral antibiotic prescriptions	31	13	18	13	21	-8	0.007
Mean prescriptions per parent	0.37	0.16	0.22	0.14	0.22	-0.08	
Mean prescriptions per GP audit record	0.33	0.14	0.19	0.11	0.18	-0.07	
Other prescriptions for minor ails	37	22	15	23	24	-1	0.111
Mean prescriptions per parent	0.45	0.27	0.18	0.24	0.25	-0.01	
Mean prescriptions per GP audit record	0.39	0.23	0.16	0.20	0.21	-0.01	
Pharmacy First prescriptions	46	N/A	N/A	N/A	N/A	N/A	n/a
Mean prescriptions per parent	0.55	N/A	N/A	N/A	N/A	N/A	
Mean prescriptions per GP audit record	0.48	N/A	N/A	N/A	N/A	N/A	

* Any value < 0.05 is statistically significant to the 5% level

The audit findings should be interpreted with caution for a number of reasons. Firstly, the follow-up data collection period for the intervention group began on the day that a participant registered for Pharmacy First. Since most registrations during the period of the JUSC project took place at the surgery, registrants were likely to be at there because they were consulting a GP or nurse. The consequent impact on apparent consultation rates following registration is not possible to determine accurately but it is likely that GP consultations in the intervention group were higher for this reason. Notwithstanding this possible bias, the focus group findings also raise issues relating to Pharmacy First mothers' preparedness to visit their GP after seeing a pharmacist (see below).

Secondly, data from the Scottish pilot minor ailment scheme indicates that it takes 18 months or more to reach "steady state"[35]. Thus the six month follow-up period that we were able to undertake in the JUSC study could only capture any early changes.

Thirdly, the fact that, although they were not registered under Pharmacy First, the control group were inevitably exposed to the PCT-wide minor ailments promotional activity means the comparison with the intervention group is not a pure one. This is true for all the evaluation methods applied to the Minor Ailments module.

Focus groups (see annex 7.1 for further detail)

Two focus groups were conducted with mothers whose children were registered under Pharmacy First (in Ilkeston) and two with mothers whose children were not registered (in Long Eaton). These indicated that many mothers were very concerned not to waste a GP's time.

> *"I don't like to think of the doctors being overstretched if it's something I can deal with myself"*
>
> *"I've found myself apologising and saying 'it's been a couple of days now so I thought I ought to come"*

They saw the pharmacist as a relatively quick and easy midway point between seeing a GP and treating a child themselves.

> *"He is more accessible"*
>
> *"You don't have to make an appointment – you can go at your convenience"*
>
> *"This (Pharmacy First) is like a little bit of a step in between"*

There was low awareness of Pharmacy First amongst the control group respondents in the focus groups, but those in the intervention group felt it had developed a sense of how to use a pharmacist's skills and acted as a confidence driver.

> *"If you've had that advice once you feel a bit more confident. You know which way to go, well I'll go back to the pharmacist and I'll know that if they can't help me I'll ring the doctor and know that I'm not wasting anyone's time"*

However, they felt first time mothers were more likely to go to their GP and there was some dissatisfaction and misunderstanding in relation to the limited list of free medications which pharmacists can provide under the Pharmacy First scheme.

[35] Sheehy C, Jones L. (2003) Direct Supply of Medicines in Scotland: Extended Monitoring of a Pilot Scheme; Scottish Executive Social Research: Research Findings No. 30

There was also some mention of pharmacists being able to refer mothers on to a GP if appropriate (or if the condition had not resolved in a certain time), and some mothers felt this gave them "permission" to seek a GP appointment.

> *"I'd feel more confident going to the doctor and saying 'the pharmacist suggested I came'"*

> *"I always go to the Pharmacy First, they're next to the doctor. I'll just explain and they'll put me through to the doctor if they can't help me"*

A small number of Pharmacy First mothers in the focus groups appeared to have seen the GP after the pharmacist if they were not happy with the range of medicines that could be supplied or the conditions under which they could be supplied (for example, the child having to be present in the pharmacy for paracetamol syrup to be given). These factors may partly explain why there was no decrease in GP consultations in the intervention group.

Overall, the focus groups indicated a satisfied view of the Pharmacy First scheme from those who had used it and a positive expectation of it from those in the control group. Positive experience of dealing with, and receiving advice from, pharmacists led to a greater feeling of empowerment when managing children's minor ailments with pharmacy support.

7.6 Community-wide Attitudes at Follow-up

As part of the 2Europe market research survey, a booster sample of mothers aged 20-29 was recruited for in-home interviews (n=40).

This found that, in the previous 6 months, 59% of the sample had visited their GP with a minor ailment, either for them or for their child, compared with 15% who had sought advice from a pharmacist and 7% who had used NHS Direct. Asked if they were more or less likely to seek minor ailment advice from a GP compared with 6 months ago, there was no significant difference in this group, although across the whole 2Europe sample (n=540) there was a slight decrease in likelihood. The most significant reason given for this was the difficulty in getting a GP appointment.

Respondents also said they were, on average, slightly more likely to see a pharmacist, but again this was not significant amongst the young mothers. There was no difference in the likelihood of using NHS Direct or self treatment for minor ailments in this booster sample.

Overall, 3% of the 2Europe sample (n=540) were aware of any self care programmes being promoted locally, although this was 4% amongst mothers of any age. Of those who recalled any programme (n=18) from the last few months, the following were recalled on a prompted basis:

Something to do with children's minor ailments:	33%
Something to do with using your pharmacy/chemist:	28%
Something to do with winter coughs and colds:	22%
Something to do with hay fever:	17%
Something to do with summer bites, stings & sunburn	0%

8. EVALUATION OF INTERVENTIONS WITH HEALTHCARE PROFESSIONALS

8.1 Key Outcome Measures

- Professional attitudes towards CHD prevention
- Professional attitudes towards management of minor ailments
- Concordance with patients on asthma care.

8.2 Summary & Implications

We compared attitudes at baseline with those at follow-up. There was no control group.

The following were the findings against our key outcome measures:

- Most healthcare professionals are comfortable about informing patients of their self care options in CHD prevention, self care of asthma and children's minor ailments
- Self care promotion is considered to be most effective in relation to minor ailments management. There was high awareness of Pharmacy First across all professional groups
- There was high awareness of stop smoking programmes, but other CHD prevention programmes were not widely promoted by health professionals
- The general practice Local Enhanced Service 'Promoting Self Care' was widely recognised. However although the new pharmacy contract specifies self care support in several essential services, none of the pharmacists interviewed mentioned this
- Awareness of the EPP was high, especially amongst GPs, but they only rarely consider it for patients with long term conditions (including asthma)

The key implications are:

- Many healthcare professionals believe their consultations already include self care; however, evidence from the interactive training sessions suggested this was not systematic and consistent and health professionals feel they need more time to promote self care properly
- Engaging clinical staff is always difficult; this was particularly the case when practices and pharmacies were preoccupied with new contracts
- The contractual incentives have resulted in general practices focussing on activities that are remunerated; thus the LES is an important innovation for practices
- The potential for the pharmacy contract to promote self care has not been fully explored, although a Pharmacy First scheme is a good vehicle for engaging pharmacists in minor ailments management

8.3 Activity Overview

As outlined in Chapter 3, the interventions with healthcare professionals were as follows:

- Engagement on self care issues with the Local Pharmaceutical Committee, Local Medical Committee and individual health professionals via letter
- Structured educational events on self care for general practices
- Linkage of self care activities with the new professional contracts for GPs and pharmacists, particularly through the development of a general practice Local Enhanced Service (LES) promoting self care (introduced towards the end of the project in November 2005) and extension of the existing pharmacy LES (Pharmacy First) to cover all of the PCT area.

The evaluation research consisted of structured telephone interviews immediately prior to the start of the JUSC project (January/February 2005) and at follow-up (May/June 2006).

8.4 Baseline Issues

The baseline research comprised telephone interviews with a sample of GPs, pharmacists, nurses and health visitors as outlined in Table 8.1.

Table 8.1: Health Professionals – Baseline Sample

Healthcare Professionals at Baseline	Number in PCT	Number Interviewed	Percentage
GP	75	16	21%
Community pharmacist	25	14	56%
Practice nurse	33	8	24%
District nurse	33	10	30%
School nurse	13	8	62%
Health visitor	22	8	36%
Total	201	64	32%

Most respondents at baseline felt comfortable about informing patients of their self care options in CHD prevention, self care of asthma and children's minor ailments, although District Nurses had less confidence in the latter two. However, most did not think current self care promotion (at that time) was effective, particularly in relation to CHD prevention. Respondents said they very rarely see adults who ask spontaneously about their risk of heart disease, with nearly a third of pharmacists saying this never happens.

It was considered particularly difficult to reach patients who are not self-motivated, and most health professionals were not aware of, or using, many of the current initiatives. There was high awareness of the Pharmacy First scheme and most respondents were aware of the Stop Smoking programmes (eg. Freshstart). However, the EPP, 'Feel Good

Look Good' and 'Walking for Health' programmes were not so well known, particularly amongst pharmacists.

There were strong levels of agreement among all professional groups regarding the importance of improved patient confidence, education and empowerment in self care but there was almost no awareness of the self care model of consultation.

There were also strong levels of agreement among GPs with the pharmacist's role in guiding patients to appropriate action, but more concern about advice from pharmacists not known personally to the GP.

As indicated in Chapter 2, full engagement of health professionals (specifically GPs and pharmacists) on self care proved difficult outside the research interviews. The self care education sessions, including the self care aware model of consultation, were intended to facilitate this engagement.

8.5 Self Care Education for Primary Care Teams

Following piloting in March 2005, three educational sessions for GPs were held in June 2005, February 2006 and March 2006. Called "A Partnership of Experts – Breaking the cycle of dependency", the 2006 events were substantially more successful than the 2005 event. The more positive atmosphere was attributed to the fact that by February 2006 the LES promoting self care was in place, and participants had a better understanding of the reasons for and benefits of attending the event (as opposed to attending simply in response to a PCT request). (See Section 3.8 for details on these events)

During these sessions, participants expressed concern that the health professional consultation should not move into self care too early since the patient might think he/she is being "fobbed off". Time needs to be given to ensuring, through creating an enabling environment, that this is an appropriate consultation in which to promote and support self care..

Part of the 'Promoting Self Care' LES was to stock and issue advice through various leaflets which support self care messages. Some GPs felt that advice on leaflets is sometimes too cautious, worrying patients unnecessarily into returning to their doctor too early. GPs can however counteract this when handing out leaflets.

Consideration was also given to looking at patients who attend very frequently so that they can be given self care messages throughout the consultation, beginning the process of "weaning" the patient off the GP and of breaking the cycle of dependency.

While barriers had included such issues as time, pressure of workload, the pressure of patients who are exempt from the prescription charge and alternatives to offer patients in the place of a GP consultation, the session concluded with the acknowledgement that all these issues had indeed been addressed and solutions found.

Those attending agreed to take the experience of the sessions back to their practices and to use the presentation delivered by the facilitator with their colleagues in the practice and nearby pharmacy colleagues. There was evidence from the follow-up interviews of at least one practice doing this effectively.

The results of the evaluation by course members are given in Annex 8.1. The first event achieved the worst scores, by far, of any event in the first two years of the Collingham Healthcare Education Centre. However, it provided very useful lessons, which were incorporated into the subsequent sessions. The success of the latter two is self evident with the mean score for the course content reaching 4.6 out of a possible 5.

8.6 Comparison of Baseline and Follow-up Measures

8.6.1 Follow-up sample profile

Structured follow-up interviews were conducted with 51 health professionals. Forty-six of these respondents had been interviewed at baseline but it was not possible to follow up all 65 of the baseline respondents. Five additional respondents were therefore interviewed at follow-up who had not been interviewed at baseline (two pharmacists, two district nurses and one school nurse). Twelve of the sixteen GPs interviewed at baseline were available for interview at follow up.

Table 8.2: Health Professionals – Follow-Up Sample Profile

Healthcare Professionals at Follow-up	Number Interviewed	Mean Time in PCT (yrs)	Mean Time in Function (yrs)
GP	12	11.75	12.83
Community pharmacist	14	7.43	9.21
Practice nurse	4	23.50	25.00
District nurse	11	11.45	14.18
School nurse	5	6.00	6.60
Health visitor	5	18.00	18.80
Total	51	11.47	13.06

GPs had on average been in the PCT (or its predecessor organisation) for longer than pharmacists – an average of nearly 12 years compared to seven for pharmacists. GPs had also, on average, been practising for 13 years, compared to nine for pharmacists. Pharmacists were the most recently qualified of all the professional groups interviewed with the exception of school nurses.

Practice nurses and health visitors had been working in their function and had been in the PCT by far the longest (>20 years and >18 years respectively), although the sample only included four practice nurses and five HVs.

Statistical tests were conducted on selected interview data with a pre-defined level of significance at the 5% level. While there were some changes from baseline most did not reach statistical significance.

8.6.2 Self care promotion

The proportion of the overall sample who felt comfortable in informing patients and carers of their self care options in CHD, self care of asthma and management of minor ailments by mothers of young children were similar at baseline and follow up.

All GPs and pharmacists at both baseline and follow-up felt comfortable providing information on CHD self care, and only one GP and one pharmacist were not comfortable in asthma, plus one GP in minor ailments. (These numbers were the same at baseline and follow-up)

There was no significant change in the proportion of the overall sample (or any professional group within the overall sample) who considered existing self care promotion to be effective, although this proportion did fall in relation to asthma management. (Table 8.3). Self care promotion was considered to be most effective in relation to minor ailments management and this may reflect the high awareness of Pharmacy First.

Table 8.3 also indicates that the great majority of health professionals see wider promotion of self care contributing to the achievement of GP and PCT targets. Fifteen respondents (29%) at follow-up spontaneously mentioned reduced numbers of GP appointments, freeing up GP time to do other things, as a key mechanism by which self care promotion could help the achievement of targets.

Table 8.3: Attitudes to Self Care Support and Promotion

		Baseline	Follow-up	Absolute change in percentage	P-value (baseline vs follow-up)*
The current level of self care promotion in primary prevention of CHD is effective	pop	64	51	6.43%	0.489
	n	26	24		
	%	40.63%	47.06%		
The current level of self care promotion in the management of asthma is effective	pop	64	51	-10.02%	0.278
	n	29	18		
	%	45.31%	35.29%		
The current level of self care promotion in the management of minor ailments by mothers of young children is effective	pop	64	51	-0.95%	0.919
	n	37	29		
	%	57.81%	56.86%		
Wider promotion of self care in these areas would help achievement of GP and PCT targets	pop	64	51	-7.11%	0.297
	n	56	41		
	%	87.50%	80.39%		

** Any value < 0.05 is statistically significant to the 5% level*

8.6.3 Awareness of self care support initiatives

Eleven out of 12 GPs in the follow-up sample were aware of the LES promoting self care support, although one respondent thought it was "related to cholesterol testing or possibly

asthma". Ten out of fourteen community pharmacists were aware of the LES. Overall awareness across all the professional groups was 71%.

This awareness was higher than for the "Joining up Self Care" programme as a whole, which had 63% overall awareness (8/12 GPs, 11/14 pharmacists, 13/25 nurses/HVs).

There was low awareness (20% overall) of any other NHS or DH initiatives in self care, although national anti-smoking campaigns, obesity campaigns and the EPP were mentioned by nurses, and the "five a day" healthy eating campaign was mentioned by one GP.

Awareness of Pharmacy First was high at baseline and increased further at follow-up in all professional groups (Table 8.4). It appears that patient feedback on Pharmacy First is very limited, although some GPs felt that "no news is good news".

At both baseline and follow-up most practice nurses reported that they "very often" see adults who do not buy OTC medication because they receive free prescriptions. Over half the GPs reported that they see such patients either "very often" or "quite often"; clearly this may impact on consultation rates for minor ailments.

Table 8.4: Awareness of Pharmacy First

		Baseline	Follow-up	Absolute change in percentage	P-value (baseline vs follow-up)*
TOTAL	pop	64	51	18.35%	0.003
	n	51	50		
	%	79.69%	98.04%		
GP	pop	16	12	18.75%	0.112
	n	13	12		
	%	81.25%	100.00%		
Community pharmacist	pop	14	14	14.29%	0.142
	n	12	14		
	%	85.71%	100.00%		
Practice nurse	pop	8	4	37.50%	0.157
	n	5	4		
	%	62.50%	100.00%		
District nurse	pop	10	11	20.91%	0.223
	n	7	10		
	%	70.00%	90.91%		
School nurse	pop	8	5	0.00%	Undefined
	n	8	5		
	%	100.00%	100.00%		
Health visitor	pop	8	5	25.00%	0.224
	n	6	5		
	%	75.00%	100.00%		

** Any value < 0.05 is statistically significant to the 5% level*

Awareness of the self care aware model of consultation increased significantly (p=0.021), especially amongst GPs. At baseline only 1/16 GPs was aware of it, whilst at follow-up 8/12 were aware.

Awareness of the Expert Patients Programme (EPP) was similar at baseline and follow-up with a small decline in all professional groups except pharmacists (36%) and practice nurses (75%). Awareness of the EPP was still >90% amongst GPs, although 80% of

those aware would still only "rarely" consider it for patients with long term conditions (compared to 75% at baseline with 25% considering it "quite often").

Awareness of the stop smoking programme "Fresh Start" was between 88% and 100% in all professional groups at baseline and 100% in all groups at follow-up. There was also high awareness of the "Feel Good Look Good" and "Ease into Exercise" programmes, with a marked increase between baseline and follow-up amongst district nurses (4/10 increasing to 10/11, p=0.013).

There was also high awareness of "Walking for Health" at both baseline and follow-up, but low awareness of active life and cookery courses at follow-up (these latter two were not included in the baseline questionnaire)

8.6.4 Supporting self care

Seven of the eight GPs aware of the self care aware model of consultation at follow-up (58% of a GP sample of 12) said they were now using it, four of whom said it was what they had already been doing:

> *I always did something like it but without the title*
>
> *I've always done something along those lines*
>
> *It tends to be what we do anyway*
>
> *It's a slight change but basically what I was doing already*

One GP commented that she was "slightly insulted" by the promotion of the model as she had already incorporated a self care aware model into her consultation and did not learn anything new from the training.

At both baseline and follow-up, most respondents in all professional groups said they only "rarely" saw patients who spontaneously asked about their risk of heart disease. This did not change between the two time points.

When probed on active recommendation of CHD self care interventions, all GP respondents promoted the stop smoking programmes with several running their own courses at the surgery. However, only four had a policy on recommending Walking for Health and only two had such a policy on Exercise for the Heart. Promotion of Pharmacy First was mostly seen as the responsibility of nursing and reception staff.

Interviews were also conducted at follow-up with four practice managers. Although two of them had been involved in the administration of setting up smoking cessation or asthma clinics, they did not feel that self care promotion was part of their role:

> *It's not my territory – should be left to the clinical staff*

I would not want to be involved more…the nurse and healthcare assistant put literature in the waiting room and change the display board

I don't have any patient contact

Practice managers did not feel that particular skills or competences in the promotion of self care were appropriate for them.

8.6.5 GP attitudes regarding minor ailments management

GPs were asked how much they agreed or disagreed with a number of statements regarding the management of minor ailments, using a 5 point scale (5=strongly agree, 1=strongly disagree). These statements were based on previous research in this area[36].

Despite the high awareness of Pharmacy First, there was a slight increase in the level of agreement that they (the GP) would rather see a patient for a minor ailment than risk missing something of potential importance, and a slight decrease in agreement regarding the patient education and empowerment benefits of providing OTC advice rather than a prescription. However, these changes were not significant and levels of agreement for all the statements regarding GP and patient roles were high. (Table 8.5).

Table 8.5: GP Views on GP & Patient Roles in Minor Ailments Management
(5=strongly agree, 1=strongly disagree)

Views on their own role and patients' responsibilities in management of minor illness		Baseline	Follow-up	Absolute change in mean
I would rather see a patient for a minor illness consultation than risk missing something of potential importance	pop	16	12	0.65
	n	16	12	
	mean	3.19	3.83	
People should rely less on GPs and more on their own common-sense regarding minor illness health problems	pop	16	12	0.17
	n	16	12	
	mean	4.25	4.42	
The key to reducing minor illness consultations is to increase the patient's confidence in their own ability to handle minor illness health problems	pop	16	12	-0.17
	n	16	12	
	mean	4.50	4.33	
By advising a patient to purchase a specified OTC medicine rather than writing a prescription I am educating them to self-manage similar symptoms in the future	pop	16	12	-0.67
	n	16	12	
	mean	4.50	3.83	
By advising a patient to purchase a specified OTC medicine rather than writing a prescription I am helping to empower patients to take more responsibility for their health in general	pop	16	12	-0.56
	n	16	12	
	mean	4.31	3.75	

[36] Morris CJ, Cantrill JA, Weiss MC. (2001) GPs' Attitudes to Minor Ailments. *Family Practice*; 18(6): 581-585

The only statement with a mean score <3 was the negative statement on GPs' unease in suggesting advice from a pharmacist whom they do not know personally. Agreement was particularly high in relation to the pharmacist's main role in minor ailments management as "guiding patients to an appropriate course of action with referral to the GP if necessary". (Table 8.6)

Table 8.6: GP Views on Pharmacist & Patient Roles in Minor Ailments Management

(5=strongly agree, 1=strongly disagree)

Views on the role of pharmacists in minor illness management		Baseline	Follow-up	Absolute change in mean
People should take more responsibility for their health by visiting a pharmacist about a minor illness before consulting their GP	pop	16	12	0.04
	n	16	12	
	mean	3.88	3.92	
The pharmacist's main role in minor illness management should be guiding patients to an appropriate course of action with referral to the GP if necessary	pop	16	12	-0.02
	n	16	12	
	mean	4.69	4.67	
I would like to recommend to patients that they seek advice from a pharmacist about minor illness health problems	pop	16	12	0.15
	n	16	12	
	mean	3.94	4.08	
I am uneasy suggesting a patient seeks advice from a pharmacist who is not known to me personally because I have no idea about the quality of the advice they may receive	pop	16	12	-0.21
	n	16	12	
	mean	3.13	2.92	

The findings reported in Tables 8.5 and 8.6 are in line with those reported by Morris et al[31] in a much larger sample of GPs (n=413), with the exception of the last two statements in Tables 8.6:

> *I would like to recommend to patients that they seek advice from a pharmacist about minor health problems*: 83% agreed or agreed strongly at follow-up, compared to 51% in Morris et al
>
> *I am uneasy suggesting a patient seeks advice from a pharmacist who is not known to me personally because I have no idea about the quality of the advice they may receive*: 33% agreed or agreed strongly at follow-up, compared to 49% in Morris et al.

This suggests more positive attitudes towards recommending advice from a pharmacist amongst the Erewash GPs as compared to Morris et al's survey across eight English Health Authorities conducted in 1999.

8.7 Barriers to Further Development of Self Care Support

At baseline the majority of respondents in all professional groups considered there to be barriers within the health service locally to the further development of self care support. This perception had improved at follow-up amongst pharmacists, and district and school nurses, although not significantly (Table 8.7).

Table 8.7: Perceptions of Local NHS Barriers to Supporting Self Care

Considers there are barriers within the health service locally to further development of self-care		Baseline	Follow-up	Absolute change in percentage	P-value (baseline vs follow-up)*
TOTAL	pop	64	51	-7.57%	0.391
	n	45	32		
	%	70.31%	62.75%		
GP	pop	16	12	8.33%	0.595
	n	12	10		
	%	75.00%	83.33%		
Community pharmacist	pop	14	14	-14.29%	0.450
	n	8	6		
	%	57.14%	42.86%		
Practice nurse	pop	8	4	0.00%	1.000
	n	6	3		
	%	75.00%	75.00%		
District nurse	pop	10	11	-6.36%	0.757
	n	7	7		
	%	70.00%	63.64%		
School nurse	pop	8	5	-35.00%	0.207
	n	6	2		
	%	75.00%	40.00%		
Health visitor	pop	8	5	5.00%	0.835
	n	6	4		
	%	75.00%	80.00%		

** Any value < 0.05 is statistically significant to the 5% level*

When asked what these barriers were, 13 respondents at follow-up (including 6/12 GPs) spontaneously mentioned financial or resource (ie. staff) constraints. However, there were also some more wide-ranging comments at both baseline and follow-up:

> *No coherent government strategy – it's too piecemeal (GP, baseline)*
>
> *The whole game plan [in self care] is lacking (GP, follow-up)*
>
> *So many initiatives being thrown at GPs it's hard to engage them (GP, follow-up)*
>
> *Short termism - not wanting to put the money in now for the future. Nurse practitioners trained to do triage were reducing GP workload, but triage wasn't included in the new contracts and not paid extra so nurses have said they will no longer take on the role until they're covered (GP, follow-up)*

Communication issues were also raised, both within the health service and in relation to patient information:

> *Delivery methods to get information to patients need to be looked at (GP, baseline)*

> *Things [are] put in place without the surgery getting to hear about it before the patients. Asthma special day was poorly thought out, aimed at younger people but run over a whole day in the working week (practice nurse, follow-up)*

Some respondents perceived there to be some isolation of roles which did not help communication. This applied particularly to Health Visitors and District Nurses:

> *DNs are now detached from practices and therefore are less aware of the general needs of the client population. If key services became geographically based then that might help (DN, follow-up)*

Pharmacy First was regarded as a positive step but patient empowerment in self care was considered difficult to achieve by many respondents because of attitudinal barriers:

> *Client and carer expectations that health professionals do stuff for them – they're resistant to making efforts for themselves. Nurses are also trained to do rather than facilitate. (DN, follow-up)*

> *Traditional methods of working - staff need to be more aware of benefits of empowering people and not frightened of that (HV, follow-up)*

> *Attitudes and training of pharmacy staff…New contract is not fully understood (Pharmacist, baseline)*

At baseline, five out of 14 pharmacists mentioned constraints on pharmacy time and the problem of how to fund such time in relation to supporting self care. At follow-up only 2/14 pharmacists mentioned this as a particular barrier within the health service locally, although it was mentioned more often in relation to their own work (see below).

At follow-up, respondents were also asked if they felt there were any barriers in their own work to the further development of self care support. 84% of all respondents (including all GPs and 10/14 pharmacists) felt there were some barriers in their own work.

When asked what these barriers were, most respondents (9/12 GPs, 8/14 pharmacists, 10/25 nurses/HVs) mentioned time constraints. There was a strong perception that promoting self care and discussing it properly with patients would take more time and *"workload is at saturation point already"*.

Even though many respondents felt that further development of self care support could free up GP time for other things (and hence help in meeting targets), doing it properly was still seen as time consuming in itself:

> *[We] do it all the time opportunistically but there's not enough time or people to set up programmes and so on (HV, follow-up)*

However, one GP commented that he couldn't really say it was a lack of time, he just had to *"remember to do it"*. Three District Nurses said at follow-up that they would need

training to feel confident in promoting and supporting self care, and one GP, one practice nurse and one pharmacist mentioned space and facilities for self care consultations as a barrier.

9. EVALUATION OF ORGANISATIONAL INTERVENTIONS

9.1 Key Outcome Measure

- Operational implications for the PCT of sustaining a "joined up" self care support programme.

9.2 Summary & Implications

The following were the key findings from the PCT management interviews undertaken at the end of the intervention period:

- PCT managers agree that support for self care is a legitimate activity and involvement in JUSC has raised the profile of self care in the PCT
- The minor ailment scheme is seen as a positive aspect of JUSC and the LES is seen as a positive outcome
- The fact that JUSC was not closely aligned with public health and primary care directorates was a barrier to full implementation of the concept of "joined up self care" in Erewash
- The impending PCT merger risks undermining progress in Erewash
- There is a confusion of concepts where self care overlaps with long term conditions or minor ailments care but is not seen cohesively
- There was disagreement concerning whether PCTs view self care support as a "nice to have" or a "must do"

The key implications are:

- A programme such as JUSC requires champions at all levels within the organisation; the Chief Executive needs to be a sponsor and other senior managers must be active supporters and implementers of such a scheme
- Before embarking on a strategy to support self care the PCT needs to:
  - Define what it means by self care support and self care
  - Identify all staff and activities already supporting self care
  - Gain professional and lay engagement
  - Link the benefits of self care support to other NHS priority programmes
- In delivering a self care support strategy the PCT needs to:
  - Find, develop and work with lay and professional champions
  - Identify and be prepared to use contractual and other levers

9.3 Activity Overview

The intervention was the JUSC programme itself and the PCT's organisational development associated with it. The PAGB and JUSC Steering Group provided some support (eg financial support for an administrative resource to assist the Self Care Programme Manager) but the organisational development issues were driven by the PCT.

The evaluation comprised structured telephone interviews of between 30 and 50 minutes with senior managers involved in JUSC suggested by Helen Galloway, Self Care Programme Manager at the PCT. These interviewees are listed in Annex 9.1 and, where comments are attributable, interviewees are referred to in this chapter by bracketed initials.

9.4 Self Care Structures & Mechanisms within the PCT

9.4.1 Respondents' involvement in JUSC & self care

There was a range of involvement in self care support during and following the JUSC programme. Three respondents (PC, RM, MC) were involved at a "strategic" level, three were involved only on specific elements of the programme – the EPP (RC), Pharmacy First (SH), or the LES (GC).

Apart from PC, HG and LB, there was a strong sense that respondents had been "brought in" to JUSC at certain points and their input comprised a short burst of activity. Everyone agreed that PC was the champion for the project (according to her, spending approximately 2 hours per week on self care issues, but more in the earlier stages). However, this was not seen universally as the best solution; not having an operational director with clear responsibility for self care and JUSC from the start may have handicapped the project. RM commented that the Chief Executive could have been the "sponsor" for the project but the project manager could not report to her effectively.

Several respondents said the "constantly changing" management team within the PCT made clear and consistent responsibility for JUSC difficult, as well as the temporary handover of project management from HG to LB to cover maternity leave.

HG distinguished between her involvement in the implementation of self care activities as part of JUSC and her involvement in the evaluation (including liaison with PMSI and the PAGB). This distinction also applied to LB. SH was involved in coordinating Pharmacy First record data collection for the evaluation, and PC was involved in liaison with the JUSC Steering Group and PAGB. All the other respondents were involved solely in implementation activity.

Respondents' ongoing involvement in supporting self care, following completion of the JUSC project, was reported as:

- Development of a self care support strategy for South Derbyshire (HG and others) within the planning agenda on Long Term Conditions (LTC)
- Continuation of the EPP and a learning manual for PCTs on self care in collaboration with Trent SHA (RC)
- Continuation of the Pharmacy First minor ailments service (SH)
- Continuation of the GP Local Enhanced Service (GC)
- Continuation of news releases and related initiatives on healthy lifestyles

9.4.2 Organisational development around self care

All respondents felt that the profile of self care had been raised as a result of JUSC and PC felt that self care had become "a bit more mainstreamed" within the PCT, but comment on specific new structures and mechanisms was limited.

Several respondents mentioned the strong link between JUSC and the PCT's strategy on ***Long Term Conditions*** (LTC). MC felt that LTC is "the natural home for self care but the challenge is significant - the EPP is only one small part". The Integrated Service Improvement Programme (ISIP) was mentioned by HG and one other respondent in relation to the promotion of self care support within the long term conditions agenda, and the improved connection with community pharmacy was considered valuable.

However, RM described the PCT's self care support structures as "embryonic and patchy" and HG and RC felt that Public Health should but did not yet include self care (although workshops in this area are planned). Although the importance of self care was now more widely recognised, no respondents described an over-arching structure for its strategy or implementation.

One respondent (non-attributable) felt the PCT's Self Care Support Strategy was not really a strategy but more a statement of ideal "desirables".

The upcoming ***PCT merger*** (six PCTs combining into one) means that "rapid change" is to be expected, but:

> *"Self care is taking a bit of a back seat due to the PCT reorganisation. I don't see a lot of self care in PCT strategies and targets" (LB)*
>
> *"The merger may water down the progress made on self care – I fear for it a bit" (PC)*
>
> *"Uncertainty regarding new PCT management may hold self care back" (GC)*
>
> *"Self care is not one of their core areas at the moment" (MC)*

SH commented that some but not all the other existing PCTs in Derbyshire have minor ailments schemes, so they are not all starting from the same position. A "wider patch" may dilute the local tailoring of schemes and for consistency "you're going to have a

more rigid model or framework". He and other respondents commented that Community Matrons could be important especially in their link to medicines use reviews and the promotion of minor ailments schemes.

RC felt there was some duplication of effort between the PCT and the SHA and more structuring is necessary to take the self care agenda forward.

RM felt that ***GP clusters*** would be key to the development of self care within the new merged PCT. (Erewash already has two natural clusters in Ilkeston and Long Eaton). GC thought that practice based commissioning would be a positive driver for self care (all 14 practices in Erewash have signed up for this) but said it was currently unclear whether the new PCT will take up the LES. HG commented that GP commissioning streams within the PCT do not include self care and they need to do this.

The fact that there had been no local GP champion for self care meant that GPs had been reluctant to become involved in the JUSC project.

9.5 Positives of Being Involved in JUSC

PC felt that, from the PCT perspective, the key positives of JUSC were the fact that it had spread self care "into all corners of the PCT" and in particular it had got primary care "signed up", in the face of some initial cynicism. The support of the PAGB with promotional material was appreciated. PC also thought the "proper evaluation" of self care support activities as part of JUSC was very valuable.

Generally, PC felt JUSC had:

- "raised the focus on self care"
- enabled the PCT to test out areas of patient education
- enabled the PCT to engage with GPs through the LES and self care aware model of consultation – although that process was just beginning

HG thought Erewash was now "ahead of the game" in self care compared to other PCTs. She also said the national dimension of the project had made it easier to get GP practices on board (RM confirmed that other PCTs might find resourcing a problem without this national dimension), and her role as the lead on self care was probably unique. RC also commented that "the PCT is usually terribly poor at setting deadlines and meeting them" and JUSC had stimulated that process and the disciplines required.

Despite not all GPs taking it on board, the ***asthma EPP and the asthma events*** were seen as a positive. Communication with GPs regarding the EPP was seen as a clear positive by RC, and contributed to getting the "political green light" for more EPP activity.

The ***"Healthy Heart" initiative*** had limited success but some resources (including the risk assessment wheel) are being used by the PCT on an ongoing basis. RM commented that the CHD and asthma activity seemed to be well received in the community.

According to SH the ***Minor Ailments scheme*** secured a much higher profile as a result of JUSC, which helped the earlier roll-out to Long Eaton without any funding barriers. Other positives were generally thought to depend on the project evaluation. MC also felt the minor ailments scheme had "moved on apace as a result of JUSC". LB also identified the impact of Pharmacy First on mothers and children and the learnings from the minor ailments focus groups as a strong positive from JUSC.

GC, LB and RM cited the general practice ***LES*** promoting self care as a tangible positive associated with JUSC.

9.6 Negatives of Being Involved in JUSC

Management change within the PCT was mentioned by several respondents as a difficulty, combined with the move to a new health centre in Long Eaton, and the introduction of new GP and pharmacy contracts (the last of which would have held back the use of the CardioRisk® programe even if it had been decided to move forward with that tool).

There some negatives associated with JUSC being a "top down" initiative championed by the Chief Executive but without enough ownership from operational directors. This was made more difficult because "Who was managing it kept changing". PC recognised that with hindsight she could have got an operational director involved to help drive it in the difficult early stages.

MC felt there was a genuine ***capacity problem*** – the PCT needs "people with time to do self care" (eg. developing a booklet for heart failure which has taken a lot of time and effort). He also felt there should have been more support or challenge for the PCT's self care strategy.

SH commented on the workforce difficulties in relation to HG's maternity leave, working to deadlines (which is difficult when calling on other member of the PCT in addition to their normal workload). He commented that there was initial enthusiasm for the CHD module "but when the ideas were tried out it didn't feel as good as we thought". It was a shame that use of the CardioRisk® computer programme did not take place as "it would be interesting to see how community pharmacists could affect uptake of healthier lifstyles with a tool like that". Uptake from patients with the printed material was difficult and the PCT needs "to think about other ways of getting the lifestyle message across, especially in the less well educated or more deprived areas". He said the dialogue with NHS Direct as part of JUSC had been useful.

Several respondents mentioned the ***difficulty of getting GPs involved***, but the importance of getting them on board early. RC suggested finding opportunities to provide them with evidence on self care including a possible half day workshop on particular aspects of the project. RM mentioned that financial incentives were likely to be important – "GPs say they need time and money more than skills".

GC also said earlier sign-up of GPs would have been helpful, as well as better sign-up from pharmacists. GPs often say they are already "supporting self care" so it is sometimes difficult getting them to attend meetings on the subject.

HG said many health professionals saw self care as "a good idea but just another thing we've got to do". PC felt it would have been better to have primary care involved earlier and RM commented the project as a whole was too "divorced" from primary care.

PC felt the other main difficulties with JUSC were:

- the amount of time needed and the scale of the project which had been underestimated by the PCT, and she thought HG may sometimes have felt she was "battling with the organisation".
- funding which was also always an issue (eg. for events).
- not having an operational director driving the initiative in the earlier stages (LB also said more support at operational director level would have helped the project messages "filter through to people managing front line services")
- a "bumpy start" with the LPC and this could have been managed better

LB felt there could have been more careful ***planning*** especially in relation to the communication strategy as well as more resources devoted to the project within the PCT. MC thought the CHD module had not been very well thought through, and the asthma module was not targeted at asthma patients who were frequent A&E attendees, amongst whom it might have had more effect.

LB generally felt the three modules were too separate – it might have been better to concentrate on one, with less to deal with simultaneously and not so many different people involved. HG felt the JUSC modules may have been too restrictive and could have been designed more closely with the PCT based on their own priorities (eg. focusing on heart failure instead of asthma).

One respondent (unattributable) mentioned some "tension" with the PAGB agenda and their expectations of the pace and deliverability of the programme. It should also be reported that one respondent got the name of the JUSC project manager wrong when referring to HG, implying a working relationship that in practice was not very close.

9.7 Sustaining Joined Up Self Care

Respondents were asked how strongly they agreed or disagreed with five statements about the JUSC project, based on a five point scale (Table 9.1).

Table 9.1: Statement Responses (n=9)
(5=strongly agree, 1=strongly disagree)

	Mean score	Range
The JUSC project has raised awareness of self care within Erewash PCT	4.6	4-5
The JUSC project will have lasting effects on the PCT	3.7	3-5
Self care is seen by my (current) PCT as a higher priority than it was prior to JUSC	4.1	3-5
Other PCTs should be recommended to implement similar projects	4.1	3-5
Self care is seen by PCTs generally as a 'nice to have' rather than a 'must do'	3.2	1-5

Table 9.1 shows there was strong consensus that the JUSC project has raised awareness of self care within the PCT.

There was also consensus, although less strong, that the project will have lasting effects on the PCT and self care now has a higher priority. MC thought the project had made people realise the need to look at "broader, different elements that contribute to self care – it's more than just the EPP, which doesn't suit everyone". (He felt the NHS was "hung up on the EPP as the only solution")

PC identified a number of structural effects associated with JUSC, especially the introduction of the LES, Pharmacy First and the EPP, but "there needs to be continued pressure or messages get lost" and health promotion budgets were often the first to be cut. HG also felt there had been a value from JUSC in terms of public involvement, and LB felt there had been better interaction with the EPP team, pharmacists and some local employers.

The wide range of views on whether self care is seen by PCTs as only a "nice to have" (rather than a "must do") reflected the fact that those respondents giving a ranking of 5 said PCTs "have too many other things to do" and attention is really only given to areas of SHA or NHS priority and "when it comes to finance people aren't going to look at self care, even though they should do".

GC thought that possible cost reduction would be a key driver of attention being paid to self care, for example if it could reduce secondary care referrals.

The positive views on this statement reflected the fact some respondents thought self care was "becoming more part of care of people with long term conditions", including the role of Community Matrons, and there is potential for more patient self testing (GC mentioned INR testing kits).

Recommendation and roll-out to other PCTs would depend on, amongst other factors, the following:

- Establishing the project as strategically important with a clear project management framework including identification of appropriate skills and accountabilities
- Agreeing a "vision" for where self care is going within the PCT and then priority areas within that (focussing on "early wins")
- Establishing a project group within the PCT with Director level support as well as senior operational managers to implement a programme
- Getting all stakeholders signed up at the start including the SHA, LPC, PBC leads, PEC, Director of Public Health, GPs and patient self help groups to promote "shared ownership".

MC commented that a lot of manpower could be wasted "reinventing the wheel" in terms of self care promotional literature; a central repository of material, possibly organised by the Dept of Health, would help. The DH should also invest more in self care training. Appetite for conferences and meetings is limited, especially in the context of the current "merger season", but dissemination of the JUSC report through Long Term Condition leads in SHAs would be helpful.

SH and RC also thought self care should be linked in more widely with the LTC agenda (including the role of Community Matrons in self care), and with secondary care, as well as through PCTs and primary care. (PC was also keen to get self care more recognised in her new role in secondary care) SH also felt the DH should develop "something between targets and just 'generally improve' self care" – maybe a toolkit. Another respondent said "pressure from the top makes things happen" and DH directives would be key. A DH "Good Practice Guide" and training package were also suggested.

In the short term the JUSC findings should also be turned into a simple PowerPoint presentation to show to health professionals and patient and community groups (such as the 50+ group) within Erewash.

Following this, three respondents suggested regional JUSC roadshows (or "learning events") linked to SHAs, and the findings disseminated via GP and pharmacist networks and the national primary care contracting team.

10. OVERALL IMPLICATIONS & CONCLUSIONS

10.1 Evaluation Overview

This evaluation concentrated on the impact of three self care modules, plus the attitudes of health professionals and the organisational issues for the PCT in implementing a joined up self care programme. In designing the study, the combination of activities around three significant and different areas of self care, which in their own right relate to major NHS targets, was deliberate. While schemes supporting self care in other PCTs have been introduced from a single component or condition perspective, JUSC went further to demonstrate the benefits of pulling several strands together for cumulative effect.

The three modules, i.e. CHD prevention, and self care of asthma and minor ailments , were designed to evaluate the impact of the programme in disease prevention, self care of a long term condition, and self care of minor ailments respectively, the last engaging with a specific target group (mothers of young children).

As examples of what might be achieved in each of these areas, there was strong evidence of increases in the following:

- Risk-reduction behaviour amongst people who received CHD lifestyle advice. Although these data are self-reported and the sample may not be entirely representative of the wider population, the levels of lifestyle change imply very significant positive impacts on CHD prevention
- Greater confidence to take care of their condition amongst people with asthma who attended an EPP course or a half day asthma taster session
- Mothers' willingness to self treat, rather than to see a health professional, for several childhood minor ailments

Amongst health professionals, some self care support programmes (including the Pharmacy First minor ailments scheme and the EPP) were well known. However, self care was sometimes seen as another part of the professionals' "burden", requiring input of scarce time and resources, rather than as a positive means of empowering patients and providing improved levels of care based on a patient-professional partnership. Contractual levers such as the general practice LES could be instrumental in changing these attitudes. Fuller engagement of pharmacists may depend on similar contractual and financial incentives.

Embedding self care in existing organisational structures presented challenges for the PCT. It is likely that a cultural shift is needed if self care is to become an integral part of PCT policy and translated into coordinated action on the ground.

The limitations of the evaluation include the shortness of the timeframe, during which it might be optimistic to expect to witness significant changes in levels or patterns of demand for particular services. Nevertheless, the findings are indicative of the issues and

opportunities to be tackled by PCTs in developing and implementing self care promotion and support.

10.2 Key Implications

Changing professional and patient attitudes towards self care is a long term process. It is likely that programmes aimed at achieving such changes will be taken up most readily by people who already adopt the desired attitude.

Amongst patients, this seems to have been the case with both the CHD module and the Minor Ailments module where the intervention groups were attitudinally different to the control groups. The implication is that additional effort or other methods will be needed to engage people who are less motivated to adopt self care behaviours. In the Asthma module, participants in the EPP and half day taster sessions had similar attitudes at baseline to respondents in the control group, but appeared to have asthma that was less well controlled, and in that respect it was a self-selected group and not drawn randomly from the wider population.

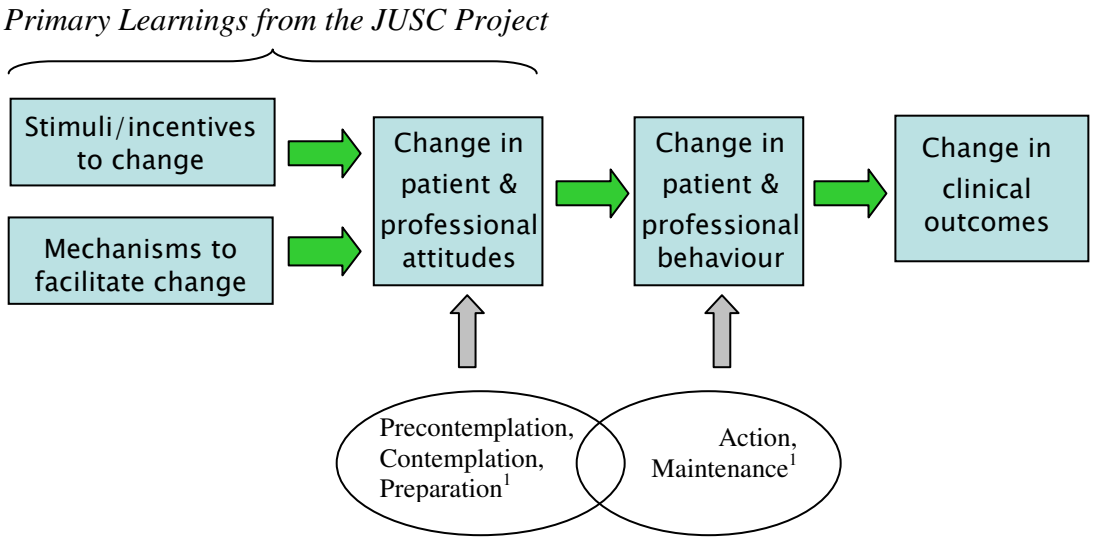
Over time, patients' greater awareness of the advice that different health and social care professionals can provide, and what they can do for themselves, may translate into changes in behaviour and ultimately changes in clinical outcomes, but this is a long term ambition.

For example, changes in outcomes related to CHD awareness and risk-reduction behaviour will only become apparent if and when rates of CHD incidence start to decline. Changes in outcomes resulting from more knowledge and confidence in self care of asthma will only become apparent if and when the prevalence of sub-optimally controlled asthma and the incidence of acute asthma attacks and/or visits to GPs or specialist nurses declines.

The key learnings from the JUSC project therefore relate to the early stages of the change process outlined in Figure 10.1. These learnings are important for the practical application of the five stages of change identified by Prochaska & DiClementi (precontemplation, contemplation, preparation, action and maintenance)[37]. In particular, activities aimed at motivation and encouragement of specific personal plans (in the contemplation stage) and assistance with the development of those plans and setting of gradual goals (in the preparation stage) may help the transition from attitudinal change to behavioural change for both patients and care professionals.

[37] Prochaska JO & DiClementi CC (1983) Stages and processes of self-change in smoking: toward an integrative model of change. *Journal of Consulting & Clinical Psychology*; 51(3): 390-395

Figure 10.1: Change Learnings from the Project



In terms of behavioural change, the WiPP remit is concerned with demand management in the NHS. In the short time frame in which we were able to track changes, and given the small number of participants that were eventually recruited, the impact of the JUSC activities on demand for different types of health services was not profound. It was not possible to examine out-of-hours (OOH) or Accident & Emergency (A&E) data since these are not available by reason for attendance; the current unavailability of such data prevents a more comprehensive evaluation of NHS resource use.

It should also be acknowledged that in the short term there could be more pressure on GP services as:

- Patients become more aware of their risk of CHD
- Patients with asthma have more confidence to seek advice from health professionals (though equally, greater confidence could mean better self care and control over asthma and which could lead to decrease in use of care services in the long run)
- Mothers are referred to a GP by a pharmacist if there is any uncertainty about their child's minor ailment

Indeed the Wanless report[38] highlighted that in the "fully engaged" scenario GP consultation rates could rise slightly, but that this produces the best health outcomes and is the least expensive scenario in the long run. More specifically, the report noted that for every £100 spent on encouraging self care, around £150 worth of benefits can be delivered in return. The report argues that the move towards "fully engaged" individuals and the health service is the only option for the real sustainability of the NHS in 2022.

[38] Wanless D. (2004) Securing good health for the whole population. HMSO: London

The approach taken in JUSC supports the view that the survival of the NHS is dependent upon a cultural change on the part of the public, policy makers, politicians and those working in the health service, which ultimately can address the challenge of meeting increasing demand with finite resources.

For both GPs and other health professionals, the risk is that initiatives in the area of self care are seen as a) yet another set of targets putting more pressure on their workload, and b) unnecessary in light of their perception (especially prevalent amongst GPs) that they already promote self care anyway. Self care therefore has to be presented as a genuine help to them in their work, with tangible benefits for both patients and clinicians in the medium to longer term. Health professionals need the understanding, the contractual incentives, the evidence, the tools and the training to promote it systematically.

The evaluation findings also suggest that other mechanisms, in addition to the involvement of health professionals, should be utilised in order to generate attitudinal change at the community level. This requires the PCT to view the development of a self care support strategy as requiring community-wide action programmes rather than health service initiatives alone.

10.3 Conclusions & Recommendations

This evaluation has shown the potential for coordinated self care support and promotion at the PCT level, but also the challenges of doing this widely and effectively.

In primary prevention of CHD, significant behavioural change aimed at risk reduction was seen in more affluent patients. Many of these patients were already interacting with the health service; community-wide engagement requires developing and sustaining relationships with other actors, including local employers, schools, social services, the voluntary sector, the media and "civil society".[39]

In the care of people with asthma and children's minor ailments, patients' and mothers' confidence improved significantly. This is likely to lead to more effective interaction with a range of different health professionals, including pharmacists and nurses as well as GPs; it is also likely to lead to greater control over their lives and health conditions there by resulting in more appropriate and lesser use of care services[40].

The JUSC programme has demonstrated that an NHS focus, even where some aspects of the three modules were delivered in community settings, inevitably has limitations in reaching people if they are not ready to think about their health or are not already interacting with the health service.

[39] "Government needs to work with others - with industry, with the media, with civil society, to have an impact on persuading more people to make more healthy choices" Rt Hon Tony Blair MP speaking at 'Healthy Living: whose responsibility?'; Nottingham, 26 July 2006

[40] National Expert Patients Programme Internal Monitoring Report (2005). Department of Health, England.

Securing maximum effectiveness from a self care support strategy depends on joining up existing resources, mechanisms and programmes. There may be opportunities for new programmes targeted at specific patient or professional groups, but the first step is likely to be to coordinate existing activities relating to self care, link them to better communication and training for health professionals, and promote such activities more assertively.

Although the JUSC project had sponsorship at the level of the PCT Chief Executive, there is a requirement for senior management "championship" of self care at an operational level, as well as the specific allocation of PCT staff and budget resources. Self care support strategies may be cost-saving in the longer term but require commitment and investment in the short to medium term. Access to OOH and A&E data would be important for a full assessment of the impacts on resources and costs.

The Wanless "fully engaged" scenario relies as much on cultural and behavioural changes within the NHS as on increased funding. Overcoming the hesitation and resistance of health professionals to further develop skills and support self care is critical.

The Essential Services component of the pharmacy contract already includes support for self care in relation to public health, long term conditions and minor ailments. PCTs can build on this by using mechanisms such as a cross-team primary care Local Enhanced Service for self care involving both pharmacists and GPs. Incentives for support of self care could be further strengthened with a nationally directed Enhanced Service framework for GPs and pharmacists through their contracts. Ways of influencing contracts for midwives, district nurses and health visitors need to be similarly explored.

The JUSC programme points the way to delivery of significant elements of the 2006 White Paper[41], which emphasises the need for SHAs, PCTs and general practices to implement mechanisms which ensure:

- Self care for maintenance of good health and lifestyle, and prevention of ill health
- Self care of minor ailments
- Self care of acute illness
- Self care of long term conditions
- Self care support including patient education and information, self care skills training, peer support networks, and a care plan approach
- Engagement and training of professionals to support self care

However, the NHS cannot deliver the culture of self care on its own. There needs to be a much greater recognition of the need for cross-agency working to target communities as a whole beyond their interactions with the NHS. As health and social care commissioning come together there must also be the potential for development of joint strategies which

[41] Department of Health (2006). Our Health, Our Care, Our Say – a new direction for community services; TSO: London

reduce the tensions currently caused within individual sectors. This would provide more opportunities to engage with the wider community.

In order to build on the learnings from JUSC, we recommend the following:

a) ***Clear leadership at national, SHA and PCT level,*** or the full potential for change will not be realised. The speed at which the NHS can mainstream support for self care will now be dependent as much on DH, SHA and PCT direction as on local adoption by GP Practices and other commissioning and provider agencies. Consequently, DH needs to provide strong central leadership through its policies, the integration of self care with other NHS priorities and the provision of toolkits on self care support.

b) ***Development of a robust self care support strategy within each PCT***, building on the knowledge now available at national level as well as exemplar projects such as JUSC. PCTs need to set a clear direction for the development of local self care support strategies, monitor their implementation and provide advice and encouragement on the use of contractual and other levers. Abstention from developing such a strategy is not a realistic option if the Wanless vision of the "fully engaged" scenario is to be realised. The strategy should be regularly reviewed and updated and needs to be inclusive and coherent across every part of the system so that self care support does not just sit in its own silo.

c) ***Identification of specific areas to be targeted within a coordinated programme at PCT level***, using the learnings from JUSC. Self care support and promotion in the three modules provides the principles for use by PCTs in disease prevention, care of people with long term conditions and the engagement of a particular target group. Integration of work on self care with other priority areas for the PCT under these headings will maximise the opportunity for strategic coherence and impact. PCTs and their local professional partners need to devote specific attention to promotion of coordinated self care support in each area and how it can contribute to improving the health and wellbeing of patients and the public. It is by joining up activities that the most gains can be made.

d) ***Ownership of components of the self care support strategy by senior members of the PCT management team.*** These senior managers (ideally heading relevant PCT directorates including Primary Care and Public Health and including the Chief Executive and Finance Director) should share information, ideas and resources on the specific agenda of supporting self care to ensure it is not marginalised or confined to only one area of activity (such as the long term conditions agenda). By taking a coherent approach there will be an opportunity to build on existing programmes and targets and new financing should not be necessary.

e) ***Resource planning & budgeting*** to ensure that self care support is adequately resourced on a sustained basis. We recommend that at least one co-ordinator within each PCT should have responsibility for self care support with cooperation from all relevant PCT directorates. It should be possible to allocate a proportion of existing budgets for programmes to support self care leading to its enhancement in the local community.

f) ***Recognition that the NHS cannot support self care on its own*** because the amount of time that any individual spends interacting with the NHS is small. The NHS needs to engage in effective strategic partnerships especially with other local community, voluntary and private agencies. Strategies to effect a change away from dependency towards greater self sufficiency need to be multi-faceted as the target audience is dispersed and heterogeneous. The only way forward is to work across all public sector agencies, in partnership with the private sector and civil society organisations, in order to build self care as a life-long habit and culture.