# The Expert Patients Programme Self-Management Course - An early intervention

## - A presentation to the Kingston Clinical Commissioning Group

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## Introduction

The purpose of this paper is to introduce the concept of Self-Care/Self-management as a central component of patient care. It will discuss the background to the need for improvements in the provision of upstream and downstream care for people with Long-term Conditions. It will outline the nature and content of the EPP Self-management Course, its benefits to patients, practice and the wider health economy.

## Executive Summary

A significant increase in chronic diseases such as diabetes, strongly correlated with rising levels of obesity and life-style choices, increasing survival rates of people with cancers and HIV/AIDS, together with an aging population is creating an increasingly difficult to manage burden on the health care services. This scenario is set to continue well into the future.

The use of behavioural change mechanisms such as the EPP Self-Management programme and its derivatives offers a cost-effective route to reducing the burden on the healthcare economy and the patient.

These interventions have been shown to improve the quality of life of the patient[i, ii, iii, iv] slow the progression of disease[v, vi, vii], and make substantial savings to the NHS and the wider economy[viii].

This document provides a detailed look at the components of such a programme, how it is constructed and the benefits that can be derived from the programme. It further describes how the service may be accessed, how it can be incorporated into clinical pathways, service reviews and other services.

The cost of providing this course per participant is in the region of £250-£300 depending on the numbers going through the programme.

The return on investment, including a Social Return on Investment, has been shown to be in the region of 10:1.

The CCG is asked to consider the increased use of self-care/self-management courses as a mainstream intervention in the management of patients with chronic disease.

# Background

## Tsunami of Need

At a recent conference, Professor Chris Ham, Chief Executive Officer of The King's Fund put forward the proposition that there will be a "Tsunami of Need" as a result of the aging population.

Improvements in medical care are leading to an inexorable increase in the number of people with chronic conditions; e.g. Cancer, Diabetes mellitus Type II, and HIV/AIDS in people more than 50yrs old.

69% of current NHS expenditure goes on the 30% of patients with Long-Term Conditions (LTCs).[ix] Furthermore, it is said that 60% of the factors affecting LTCs are classified as life-style issues and are, to some extent, amenable to behavioural change.

In order to meet the challenges that this 'Tsunami' poses, we need to refocus from a 'sickness' service to an 'upstream – preventative and self-care service.'

To this end, the Expert Patients self-management initiative was proposed in the 1999 White Paper 'Saving Lives: Our Healthier Nation' and in The NHS Plan published in July 2000.

A pilot scheme ran from 2001 to 2004 and the programme was mainstreamed in the UK between 2004 and 2007. It was introduced in Kingston in 2004.

## >59,000 Kingston residents with one or more Long-term Conditions

From a total population of ~190,000 registered with a Kingston GP there are an estimated 59,000 Kingston residents with one or more Long-term conditions.

Kingston residents live, on average, four years longer than the national average. As those aged over 65 years tend to have a least one chronic condition, this will result in an increasing burden for the local health economy and a poorer quality of life for those lives lived with a concomitant long-term health condition.

Levels of obesity in the general population are already at worrying levels and are set to rise, leading to an even greater impact on health and well-being. Related to this, diabetes is also on the rise and will increasingly become a greater burden to the health economy.

# The Expert Patients Programme Self-Management Course

## Structured Self-Management Course

The Expert Patients Programme Chronic Diseases Self-Management Course (EPP CDSMC) is a structured self-management programme providing six once-weekly sessions lasting for two and half hours including a substantial break in the middle of the session.

It is a lay-led course, delivered by volunteer tutors who, themselves, have participated on the course and been subsequently trained to deliver the course. Being lay-led is an important feature of the course, as it allows for a high degree of role-modelling: a key aspect of the course.

It should be emphasised that the lay-tutors do not offer medical advice and he or she delivers the course from a highly structured and scripted manual. Any requests for additional medical advice or information are always referred back to the healthcare professional responsible for the participant.

The goal of the course is to effect behavioural change in the participant. This is achieved through giving the participant the confidence and tools to improve their self-efficacy and adopt healthier approaches to their daily lives and symptom management. The concept of 'Self-Efficacy', as described by Albert Bandera[x], lies at the heart of the Self-Management Programme. It enables and empowers the participant to take more responsibility for their lives and their condition; gives them the tools and confidence to change their behaviour and adopt healthier and more effective life-styles with the associated benefits.

## Contents

### Group discussions

The course consists of between 8 to 16 participants. Group discussions allow participants to explore difficult issues and solutions; helping each other with problem-solving and supporting each other during this time of exploring new ways of viewing their world and their future. Mutual support is an important motivator in developing insightful behaviour.

### Short talks

Topics are introduced through a series of short presentations by the tutor/facilitator.

### Action-planning/Goal-setting

Action planning represents a key component of the course. It teaches participants to set realistic goals. It helps bolster their confidence in achieving simple goals on a regular basis; thus encouraging them to become better able to take control over their lives and master activities in a way that has, perhaps, been lost prior to the course.

### Problem-solving

Problem-solving is a second important component of the behavioural change paradigm. It shows the participants that problems do not have to be a reason for failing to act but, given a structured

approach, the participants can have the confidence and skill to approach problem-solving in a much more positive way.

### Free-thinks

This affords the participants an opportunity to reflect on issues, actively participate in the solution of problems, and experience the positive feedback derived from helping each other in gaining insights and solving problems.

### Role-modelling

The use of lay tutors to deliver the course and the requirement that they have attended the course and, themselves, have a chronic health condition is a key component of the course construct. The tutors/facilitators are continually modelling desirable behaviour to the participants. The effect of this modelling behaviour is that there is a much greater degree of acceptance to the course content and the changes it is attempting to bring about than if the same advice were delivered by a health professional. This is because the health professional will often be perceived as not 'understanding' the issues that the participant has to contend with.

### Topics addressed on the course:

***Relaxation/Cognitive Symptom Management***

***Handling difficult emotions [dealing with the negative emotional aspects of having a LTC]***

***Fitness & Exercise***

***Better Breathing***

***Managing Fatigue and Pain***

***Healthy Eating***

***Future Plans for Healthcare***

***Communication skills***

***Medication***

***Depression***

***Making treatment decisions – evaluating treatment options***

***Working with Healthcare professionals***

### Handbook – 'Self-management of Long-term Health Conditions: A Handbook for People with Chronic Disease' by Kate Lorig et al.

This handbook is given to each participant. An audio version is available for those who have visual or reading difficulties. The book has also been translated into a number of other languages. During the course, the participants are requested to read chapters relevant to that day's session and the

forthcoming session. They are encouraged to use the book as a resource: to dip in and out where most applicable, where and when relevant.

### Regular reunions for graduates of the programme

Regular reunions are organised to enable past participants to meet up with each other, refresh and rehearse topics that have been raised in the course, and to help reinforce the behavioural changes that were introduced during the course.

It is hoped that, relying on volunteer course graduates, a regular meeting point can be established; such as a monthly "EPP Treff". This would provide further support for those that feel they need additional help in self-management tasks.

## Referral/Recruitment Routes

### GP Referral

A GP referral system was disseminated to all GP practices during 2009-10. Presentations to the larger practices were conducted at the same time in order to introduce the programme and the referral package. Referrals from GP have followed from that initiative.

Disease specific referrals have been made (particularly from the Diabetes Long-term Conditions Register) in order to assist practices in meeting Local Enhanced Service Agreements.

Where the facilities allow, the EPP Self-Management Course has been conducted at the local Medical Centres, thus affording those GP practices the opportunity to offer their patients this service within those familiar surroundings. This enables the Practice to offer the EPP Chronic Diseases Self-Management Course as something they are offering their patients.

### Practice-based information and referral, e.g. practice nurse referral

Principally, leaflets and posters in surgeries and with practice nurses leading to referrals and self-referrals.

### Referral from secondary care settings

Presentations at a variety of clinical meetings, patient treatment programmes (such as Pulmonary Rehabilitation Courses, etc.) and special interest groups within the secondary care settings. The EPP Coordinator takes active part in the delivery of courses aimed at specific groups.

### Self-help/Special Interest Groups

Regular visits and presentations are made to special interest groups within the borough to inform those groups of the availability of self-care/self-management and how to access the service.

### Self-referral

Leaflets/flyers and posters are regularly disseminated around the borough in pharmacies, libraries, local authority premises etc. These inform the public of the service and invite them to make contact using a Freephone (0800) number, email or Freepost service.

## Graduates from the programme as an invaluable resource to the community

Graduates from the programme are regularly invited to participate in a variety of different activities in support of the health service and local community. This may be in the form of being a patient representative on clinical pathway redesign, volunteering to be trained to become a tutor/facilitator for the programme, or some other supporting activity within the community. Participants go on to become 'champions' of various other programmes, are involved in formal consultations , community researchers; driving improvements in their own health and helping to increase capacity in their communities.

## Current provision and performance

In 2010-11 there were 4 courses held leading to 44 participants completing the course.
The number of courses rose to 5 in 2011-12, with 74 completing.
The prime cause of the low numbers initially was a shortage of volunteer tutors.

This year, to-date (May 2012), 42 participants are enrolled on two courses. A further 6 courses are planned for this financial year. That should result in approximately 115+ additional participants completing courses in this financial year. There are 194 people on the waiting list, but only a small number will accept an offer of a place on a course. This is due to a variety of reasons; including not being available for all or part of the course dates, not being well-enough to attend, not able to attend on that particular day of the week etc.

The average age of participants was 61.5yrs.
Gender distribution was 65% female, 35% male.
Based on an end-of-course questionnaire completed by all participants, 80.6% were satisfied or highly satisfied with the course.
82% of participants felt that they had benefitted or greatly benefitted from their attendance.

Attendance data is being collected from A&E, Outpatients and GP practices both for the 12-months prior to completing the course and, again, for the 12-month post completing the course.

There are currently four volunteer tutors/facilitators available to deliver the Self-Management Course. A further two potential tutors have been identified and will be interviewed in the next few days. If they are found to be suitable, they will undergo the four day training to enable them to deliver the course; thus increasing the service capacity by two courses per annum.

## Initial Outcomes

- ### Reduction in the number of GP practice appointments[xi]
  A preliminary analysis of the limited local data available has shown the following results: GP attendance: from 237 visits in the 12 months prior to attending a course to 189 in the 12 months post attending a course = 20% reduction[xii]. Nationally, 10% has been reported.

- ### Reduction in the number of A&E and Outpatient attendances
  Hospital attendance: 180 visits for the 12 months prior to attending a course to 70 for the 12 months post attending a course = 62% reduction[xiii].

- ### Improved self-efficacy and self-confidence
  A brief screening tool, the Stanford 6-item Self-Efficacy for managing chronic disease instrument showed a 34% improvement in scores after attending a course; from an average score prior to the course of 5.39 to 7.24 subsequent to attending the course.

- ### Other outcomes[xiv]
  Improvements in quality of life
  Improved health status
  Improved psychological well-being
  Higher levels of energy/lower levels of fatigue
  Improved partnerships with health professionals

## The Role of the Expert Patients Programme Coordinator/manager

The EPP Coordinator is currently responsible to the DPH through an Associate Director of Public Health.

The role of Expert Patients Programme Coordinator/Manager has four main responsibilities.

- To be a lead specialist for EPP Chronic Disease Self-management and to champion and disseminate the values of CDSMC and other self-management tools to all interested stakeholders in the local community.
- To provide strategic planning and operational management of the programme in order to deliver a well-structured programme and ensure that milestones and outcomes are achieved.
- To devise and implement a comprehensive action plan for the provision of the EPP Self-management Course and similar courses to meet the needs of and requirements for the management of long-term conditions in the Kingston area.
- To be responsible for supporting the people delivering the Stanford Chronic Diseases Self-management Course (CDSMC).

Further details of role and responsibilities can be found in the Appendix.

# Future possibilities

## Disease specific courses

- X-pert Diabetes Course (not to be confused w/ Desmond but complementary to)
- Chronic Obstructive Pulmonary Disease & Breathlessness

## Other possible courses that could be made available (these would require cross-training or conversion training and are not currently on offer within Kingston upon Thames Borough)

- Persistent Pain Programme - - incorporates other pain programme material into CDSMC
- New Beginnings - w/ or recovering from mental health conditions – two tutors are currently trained to deliver this course
- Supporting Parents Programme - carers of children w/ LTC
- Looking After Me - A self-management course for carers – this is a key social issue at this time
- SAM - recovery from Substance & Alcohol Misuse
- Forward Steps - people claiming health-related benefits/return to work
- Wise Up - for Health Care Professionals
- Staying Positive - for young people
- Co-Creating Health - Self Management Programme
- Caring with Confidence
- Self-Management Courses in other languages
    - Hindi
    - Bangla
    - Bengali
    - Cantonese
    - Greek
    - Punjabi (G)
    - Punjabi (U)
    - Turkish

## Re-designing clinical pathways

The EPP Self-Management Course has been included in the clinical pathway on the redesign of a community rheumatology service. This has enabled clinicians to be made aware of the role and benefits of self-management as an intervention at various stages of the clinical pathway.

There are opportunities to include Self-Management in the clinical pathways of other services.

# Works closely with existing community organisations

The EPP Coordinator and team work closely with a variety of community organisations. In particular, every effort is made to offer the Chronic Disease Self-management Course to all sections of the community, especially the hard-to-reach sections, ethnic minorities and others. There is a close cooperation with other agencies within the borough, including community engagement staff within the Kingston Borough Council/One Kingston.

## Participants' comments:

- "I am now able to enjoy life again"
- "I enjoyed the course and found it interesting and helpful in lots of ways."
- "I have just completed the EPP course and would like to recommend it to other people living with long-term medical issues."
- "Excellent – thought this was a valuable experience."
- "For the last ten years I am trying to lose weight because I am eight stones overweight. This affects my blood pressure and my back problems. I tried different diet. I always started them on Monday and finished two or three days later. On the course I have learned how to do my action plan and how to solve the problem. Today I am two stones lighter. Thank you!"
- "Thank you for the course, I am now planning to go back to work."

## Quality assurance and performance monitoring

### Annual assessments and supervision with on-going training

All tutors have to undergo annual supervision, incorporating training in facilitation, delivery skills, public speaking etc. They also have an annual assessment of their delivery skills during a complete 'live' session.

### SS2Q Quality

The course is run to a strict quality protocol (SS2Q) and meets QISMET standards for its organisational and operational performance.

### Participant feedback

All participants are requested to complete an end-of-course questionnaire. This collects their experience of the operation of the course, their views on the tutor delivery, utility of the course, subjective experience of the course etc. This feedback is collected and collated in order to monitor the performance of the course, measure perceived utility and satisfaction, and swiftly identify any issues that need to be addressed. Participants that drop out before completion are contacted to identify the reasons for their leaving the course.

### Tutor feedback

Tutors are similarly asked to feedback at the end of each course. This allows the EPP Coordinator to identify any issues with the facilities or venue and any support requirements the tutors may have.

## Financial implications

Using the financial model developed by the Department of Health and the EPP CIC[xv] it can be shown that, with the improvements in healthy behaviour and reduction in utilisation of healthcare facilities, a return on investment of around 10:1[xvi] is achieved. That is to say, for every £1 spent providing the Self-Management Course, £10 can be saved by the NHS and society at large.[xvii]

The cost of providing a place on the EPP Self-Management Course is in the region of £250-£300. If the numbers are scaled up appropriately, the cost per course participant would be reduced accordingly.

## Summary

There are in the region of 59,000 people in Kingston who could benefit from attending an EPP Self-Management Course.

Approximately 2000 patients each year are added to the Long-Term Conditions Register.

These numbers are going to continue to grow as obesity; rising levels of diabetes, other life-style predicated chronic diseases and an aging population make a greater impact on the local health economy.

The EPP Self-Management Course and its derivatives can make a significant contribution to reducing the impact of these trends.

## Recommendations

To meet the needs of the local Long-Term Conditions population and in support of the local Health Care Services, the EPP Self-Management Programme and its derivatives could play a greater role.

Appropriate resourcing would result in substantial gains in patient well-being and savings to the NHS together with a significant Social Return on Investment.

It is requested that the Board support the provision of the Self-Management programmes described in this presentation and consider increasing the level of investment.

# Appendix

The EPP Coordinator/manager:

- Works in cooperation with other stakeholders in Kingston to develop a long-term conditions strategy.
- Organises EPP courses, books venues and ensures that all resources required, including refreshments, are available for the course. This will include course handbooks, printed forms and other materials.
- Participants are recruited to the courses by establishing and building relationships with local services: these may include GP practices, local secondary care facilities, community and hospital health services, local voluntary organisations and special interest and disease-specific support groups.
- The programme is delivered to take account of minority groups, difficult to reach audiences, non-English speakers, refugees, asylum seekers and other marginalised groups. EPP values and respects diversity and endeavours to ensure that all volunteer tutors and participants are welcome irrespective of their sex, sexual orientation, marital status, race, religion, age, creed, colour, ethnic origin, disability or real or suspected HIV/AIDS status.
- Monitors outcomes and participant satisfaction using a variety of tools and reports regularly to management and other interested partners and stakeholders.
- Is responsible for the drafting of policies and procedures for supporting volunteers: with reference to relevant and current best practice.
- Recruits potential tutors from those who have participated on a self-management course and have expressed a desire or the willingness to become a volunteer and have demonstrated that they have the aptitude and suitability for the role.
- Conducts interviews and other recruitment procedures in coordination with HR in order to ensure a fair, equitable and transparent recruitment policy. This will include CRB and reference checks.
- Provides training, support and supervision for tutors of the programme and to develop their skills and facilitate their development within the self-management arena to appropriate levels.
- Provide regular opportunities to discuss the programme and to develop their skills and knowledge of self-management training.
- Ensures the prompt payment of tutor expenses in accordance with PCT procedures for managing the budget of the programme.
- Delivers the course as a tutor or acts as a backup tutor where required.
- Organises reunions and establishes, where possible, a facility for regular meetings for course graduates.
- Adheres to strict quality criteria based around the National EPP Implementation, Training and Support Framework for Lay-Led Self-Management Programmes contained within “Stepping Stones to Success”.
- Designs and produces publicity materials and distributes these within the community.

- Gives presentations and informal talks to all interested parties, including NHS Kingston staff, GP Practice clinicians and support staff, voluntary sector and other community groups, informing them of the programme and its benefits to the health and well-being of the patient and the wider health economy and community at large.

## Evidence Base and Policy Documents

Healthy lives equal healthy communities: EPPCIC February 2011
Route Map for Sustainable Health: NHS Sustainable Development Unit February 2011
Measuring Impact in Health Improvement: The Local Government Group February 2011
Managing sickness absence in the NHS: The Audit Commission Health Briefing February 2011
Recognized, Valued and Supported: Next Steps for the Carers Strategy: Cross Government publication November 2010
Healthy Lives, Healthy People: Our Strategy for Public Health in England: Government White Paper, November 2010
The Quality of Care in General Practice: The Kings Fund, October 2010
Self-Care Reduces Costs and Improves Health - The Evidence: EPP CIC, June 2010
Liberating the NHS: Government White Paper July 2010
Self-Care: A National View in 2007 compared with 2004-2005: Department of Health commissioned study, June 2007
Research Evidence on the Effectiveness of Self Care Support: Department of Health, December 2007
Improving Care for People with long Term Health Conditions.: Department of Health, 2010
Incentivising wellness: improving the treatment of long-term conditions: The Policy Exchange, November 2010
Commissioning Mental Wellbeing: A leadership Brief for Boards and Senior Managers: The International School for Communities, Rights and Inclusion - University of Central Lancashire, November 2010
Avoiding Hospital Admissions: what does the research evidence say? The King's Fund, December 2010
Applying Behavioural Insights to Health: The Cabinet Office, Behavioural Insights Team - December 2010
Saving Lives: Our Healthier Nation – (Government White Paper HSC 1999/152 [introduced EPP]) 6th July 1999
The NHS Plan – July 2000
The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century – 14th September 2001
Choosing Health – (Public Health White Paper) 2004
Supporting People with Long Term Conditions: An NHS and Social Care Model to support local innovation and integration – DH 4230 – 5th January 2005
Self Care - A Real Choice; Self care Support - A Practical Option. Department of Health January 2005
Our Health, Our care, Our Say - White Paper January 2006
Self care for people with long term conditions – November 2006
Supporting people with long-term conditions to self care. A Guide to developing local strategies and good practice. Department of Health 2006
Your Health, Your Way - A guide to long term conditions and self care. 2nd November 2008 (launched on NHS Choices)
Self care support for commissioners and providers – 13th May 2009

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[viii] EPP CIC (2010).'Self-Care Reduces Costs and Improves Health - The Evidence'

[ix] Raising the Profile of Long Term Conditions Care (2008) dh_082067

[x] Bandera, A. (1994). Self-efficacy. In.V.S. Ramachaudran (Ed.), *Encyclopedia of Human Behaviour* (Vol. 4, pp 71-81). New York: Academic Press

[xi] EPP Annual Report 2009-2010.

[xii] Unpublished summary data

[xiii] ibid

[xiv] The Health Foundation (2010). Helping People help Themselves: Evidence about supporting self management.

[xv] DoH (2011). Making the case for self care education.

[xvi] PSSRU reference costs 2009

[xvii] Social Return on Investment: EPP CIC Evaluative SROI (YE Mar 2010)