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# Expert Patients Programme

Community Interest Company



## The Expert Patients

## Programme

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Toronto November 2009



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# Why self management and what is an “expert patient”

- Over 66% (c 100bn €) of all health expenditure in England is on people with long term conditions.
- No-one has more expertise in an individual persons condition than that person – they are the “expert patient”.
- But there are skills, knowledge and behaviour changes that can be learned that can assist the individual and improve quality of life.



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# What is the Expert Patients Programme - EPP

- ↘ The original course content is the Chronic Disease Self Management Programme (CDSMP) that was compiled and evaluated by Prof Kate Lorig and licensed by Stanford University to the English Department of Health in 2002
- ↘ The CDSMP is delivered all over the US, Canada, Australia, Hong Kong and in many other countries and languages worldwide
- ↘ Since 2002 in England a number of further derivatives and delivery methodologies have evolved



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# What is the Expert Patients Programme?

A series of self-management courses for people living with a long-term health condition that offer a tool kit of fundamental techniques to help participants manage their condition better on a daily basis.



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# Complements the skills and expertise of health professionals

The aim of the course is to equip participants with the confidence, skills and motivation to manage their health better, co-work with social and healthcare professionals and take control of their lives.



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# What is the Expert Patients Programme Community Interest Company?

The Expert Patients Programme pilot was launched by the NHS in 2002.

Following the success of pilot, EPP was Established as a Community Interest Company on 1<sup>st</sup> April 2007

Over 5,000 courses have been delivered to date to over 70,000 participants.



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# What is EPP and who are EPP CIC

- EPP is Expert Patients Programme which had Stanford CDSMC at its centre
- EPP CIC (from April 2007) is now the social enterprise company who have the job to expand this ....and much more.



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# EPP CIC Vision

**To establish the principle of individual self-management as a recognised public health measure, delivered in a cost effective, sustainable way.**

The aim of self-management is to improve an individual's quality of life.



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# Public policy context – Prime Minister Brown – 7th Jan 2008

“....It will not be the NHS of the passive patient - the NHS of the future will be one of patient power, patients engaged and taking greater control over their own health and their healthcare too.....)

“.....managing their own conditions;  
taking advantage of support offered by GPs and nurses in the home or on the high-street;  
exercising more control over their lives and care;  
becoming more focused on what they eat and whether they participate in sports and exercise....more conscious of their own choices, and encouraged and better supported in making them.  
And as more of us live longer we need to put support in place to help us all stay active into old age, and thus to stay healthy - adding life to years...not just years to life.....”



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# Darzi – Next Stage Review and public health direction

- Focus on wellbeing
- Links clinical and psychological therapies
- Centred around patients (patient engagement)
- Self care everywhere
- Greater emphasis on local commissioning



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## Forecasting the Future Economic Burden of Current Adolescent Overweight: An Estimate of the Coronary Heart Disease Policy Model

Results. ... Current adolescent overweight is projected to result in 161 million life-years complicated by obesity, diabetes, or CHD and 1.5 million life-years lost. The cumulative excess attributable total costs are estimated at \$254 billion: \$208 billion because of lost productivity from earlier death or morbidity and \$46 billion from direct medical costs. Currently available therapies for hypertension, hyperlipidemia, and diabetes, used according to guidelines, if applied in the future, would result in modest reductions in excess mortality (decreased to 1.1 million life-years lost) but increase total excess costs by another \$7 billion (increased to \$261 billion total).

Conclusions. Current adolescent overweight will likely lead to large future economic and health burdens, especially lost productivity from premature death and disability. Application of currently available medical treatments will not greatly reduce these future burdens of increased adult obesity.

Lightwood, American Journal of Public Health, 2009



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# What is self management training

- ✚ Typically, a six/seven module group intervention (course module)
- ✚ Delivered weekly in community venues
- ✚ Each module 2.5 or 3.5 hrs
- ✚ 10 – 15 participants, lay tutors
- ✚ Courses for health professional and young people use different formats



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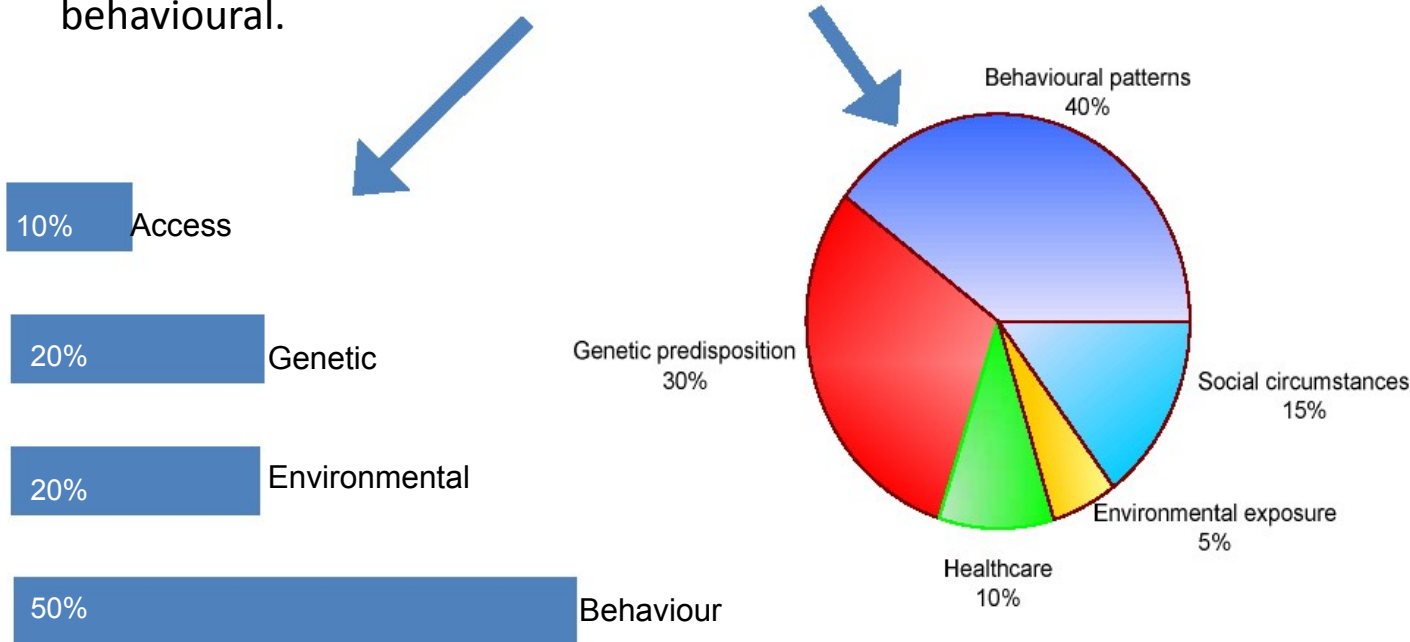
# Course participants learn how to:

- Set goals, problem solve and make action plans
- Build their confidence
- Identify shared experiences with others
- Develop their communication skills
- Manage their emotions and daily activities
- Manage relationships with family, friends, work colleagues, care teams and health care professionals
- Find health resources
- Understand the importance of exercise and healthy eating
- Manage fatigue, sleep, pain, anger and depression.



# Factors that affect health

Factors that affect health and mortality are principally behavioural.



McGinnis et al.  
Health Aff (Milwood) 2002;21(2):78-93

Source: IFTF, Center for Disease Control and Prevention

Pfizer Health Solutions



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“It is not enough for the physician to do what is necessary, but the patient and the attendants must do their part as well, and the circumstances must be favorable.”

*Hippocrates, Fifth Century B.C.  
(Chadwick, 1950)*



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## The 'burden' of long term conditions

- 80% of heart disease, stroke and type 2 diabetes, and 40% of cancers could be avoided if common lifestyle risk factors were eliminated
- The cause of 86% of deaths and 77% of the disease burden in Europe
- The conditions are linked by common risk factors, underlying determinants and

## opportunities for intervention

- Almost 60% of the disease burden in Europe is accounted for by seven leading risk factors:
  - high blood pressure
  - high blood cholesterol
  - overweight
  - low fruit and vegetable intake
  - tobacco
  - alcohol
  - physical inactivity

Source: The European Strategy for the Prevention and control of noncommunicable diseases  
WHO September 2006



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## EPPCIC structure

- 130 staff, 5 regions
- Most of 130 UK PCT's are "customers" to some extent
- We deliver 600 courses pa ourselves
- We assist delivery of c. 2000 courses pa
- Assistance given
  - Tutor training, supervision and assessment
  - New courses to meet specific needs
  - Materials updates, newsletters and professional development



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# Market leaders in developing specific new programmes

EPP CIC can design:

Courses, Bespoke sessions and Workshops

We are experienced in working with hard-to reach communities and staff are trained to deliver courses in over nine languages.



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# Lay leadership and patient engagement

- Tutors normally not health professional
- Recruited from participants
- Peer representatives (as is EPP!)
- Trained by EPP trainers
- Course designed to be lay delivered
- Can progress further
- Capacity at community level and a new form of work



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## What is new

- Focus is now on competency of lay tutor
- Competencies are based on framework for all health trainers and other staff throughout the health service
- Developed in consultation with lay tutors, commissioners, academics and accrediting bodies.



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## Some of the courses now available are:

- Carers courses: Looking after me and Supporting parents
- WISE UP which explains the EPP for social care and health professionals
- Forward steps
- Persistent pain
- New beginnings
- Support for people in recovery from substance and alcohol
- Positive self management
- Young peoples workshops
- and several disease specific products



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# Other self management applications

- Reduced time off work and health consultations
- Retention of experienced staff with long-term health conditions
- Increased energy and self confidence
- Reduced pain, tiredness, depression and isolation



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# Optimises opportunities for employment

Helps people to come off benefits and back into paid employment.

Skills learned often help participants become more effective in the workplace.



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# DH Internal Monitoring

## – Key Findings 1

- ↘ 16% fewer admissions to A&E departments
- ↘ 9% fewer visits to GPs and outpatients
- ↘ 10% increase in taking medicines as prescribed
- ↘ 15% increase in visits to pharmacists
- ↘ 6% increase in number of people using health information
- ↘ 33% increase in number of people feeling better prepared for consultations with health care professionals



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# DH Internal Monitoring

## – Key Findings 2

- 30% of people showed significant reduction in feeling of **depression and ‘lacking in energy’**
- Felt intensity of **pain, breathlessness, tiredness and depression** was less for 38% of people
- Increase in **confidence** levels for 45% of people that they would not let pain, breathlessness, tiredness or depression interfere with their lives
- 17% reduction in number of **days off work**



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# On-going Research

## **National Centre for Primary Care Research and Development with Universities of York and Manchester : Evaluating the EPP.**

- Randomised controlled trial. A major study looking at processes, clinical & cost-effectiveness, and will have an embedded qualitative study of the EPP.
- A sample size of 700 people from across the country have been involved. The results published in early 2007. This study is comparable with the largest studies developed at Stanford and will contribute to international debate.



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# Evaluation

- ↘ Our traditional numbers are supported in respect of impact upon the individual.
- ↘ Our traditional numbers are questioned in respect of impact on health services utilisation



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# Criteria for effectiveness

## ↙ Outcomes:

- Health status
- Disease process
- Health care use, scheduled + unscheduled
- Mortality
- Cost effectiveness



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# More recent analysis of the NAPC RCT - cost effectiveness

- ✦ The EPP in England shown to have 94% probability of being cost effective based on costs of approx £250/300 per participant based on improved QoL



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# More recent analysis of the NAPC RCT - disease progression

The present results suggest that the Expert Patients Programme may have a protective effect on health-related quality of life for patients with poor health or low confidence. The course can help such patients to resist a deterioration in their health-related quality of life that would otherwise have occurred.



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## More recent analysis cont...

This study replicates previous findings that the patients' underlying conditions do not predict any difference in outcomes of the self management intervention.

This result strengthens the argument that self-care support can be provided on a generic basis, which may be easier and more efficient to provide.



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# Question

- If patient confidence and well being is improved, how can this be translated into behaviour change in respect of health service utilisation and personal management of condition?



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# Answer

Greater focus on

- Bio-medical
- Challenging erroneous beliefs
- Quality of delivery

The practical application of CBT techniques to management of condition as well as lifestyle.



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# Answer

Greater focus on

- Engagement and understanding of clinicians and health professionals

Not just a course but service redesign to address inflexibilities in care pathways



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# The dominant paradigm for motivating behaviour change

Most healthcare staff believe that explaining why patients should act in certain ways will lead to changed health behaviours.

They believe that long term benefits will motivate good self-management.

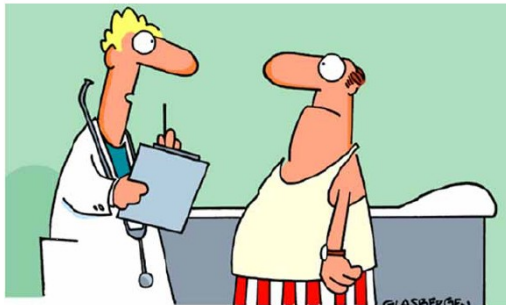
If it does not work patients must be, or stupid or too lazy to save themselves.

For some patients it does produce change.

BUT much less commonly in those with the highest burden of illness.

50% of cardiac illness is manifest in the 10% most deprived of the population.

More 'educational' risk screening and prevention programmes and social marketing will probably increase this inequity.



**“What fits your busy schedule better, exercising one hour a day or being dead 24 hours a day?”**



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# Why do we have a problem of increasing poor health?

40% of the British Adult population never engage in any moderate physical activity. (Household survey)

Would you exercise regularly if your life depended on it? NO = 64%

Do you find exercise fun? NO = 96%

BHF Survey 2007, n=2100



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# Behavioural psychology

BEHAVIOUR THAT IS REWARDED INCREASES IN FREQUENCY

Reward = anything that gives you pleasure.

The more you are rewarded the more likely you are to do it again ...and again ...and again ...and again... for ever.

BEHAVIOUR THAT IS NOT REWARDED FADES OUT (EXTINGUISHES)

BEHAVIOUR THAT IS PUNISHED ALSO REDUCES OR STOPS - but not as completely as behaviour that is ignored and not rewarded. Changing health behaviour through fear is less effective.



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# Behavioural psychology: using rewards

Build a reward into a patients' goal.

Self-recording intrinsically motivating - setting daily goals and, ticking of targets as they are achieved is rewarding for most people.

Make sure doing a goal is not punishing (unpleasant). If it is reduce it until it is 'just right'.

Make the whole process fun and be genuinely rewarding

Longterm maintenance- behaviours will not remain if they become unpleasant or unrewarding,

We do all that (?)



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## 7 actions required to help people change their behaviour

Change unhelpful beliefs - misconceptions, frightening and wrong knowledge about the illness that lead to poor coping attempts, anxiety and depression

Identify and change unhelpful coping actions – often driven by misconceptions, over activity-rest cycle, symptom scanning, fear avoidance

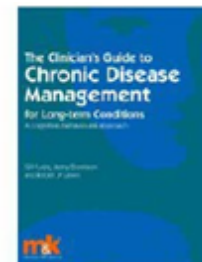
Motivation – making change enjoyable

Boost confidence (self-efficacy) – set small goals that the patient regards as worthwhile and ‘about right’ build up as patients succeed

Control – increase feeling of control over the illness and personal life.

Improve knowledge of self-management - using medication properly, lifestyle etc.

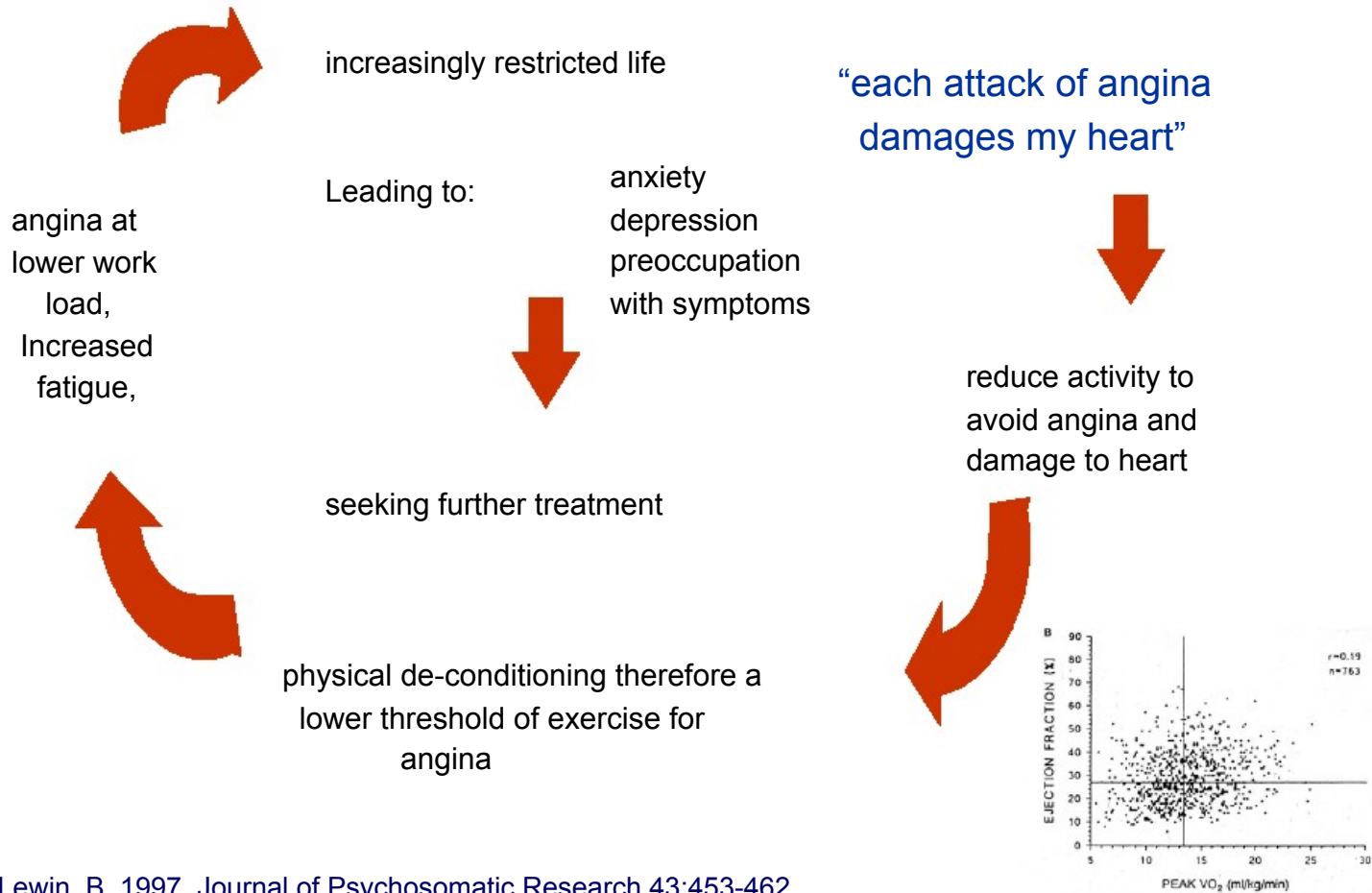
Identify and treat anxiety & depression – fear and hopelessness



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# How do misconceptions lead to more disability and use of the health service?



Lewin, B. 1997, Journal of Psychosomatic Research 43:453-462



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## So EPP's actions

- Course redesign to address in more practical ways bio-medical, belief systems and clinicians expertise
- Focus on quality of delivery – change from process to output
- What are the key skills a lay tutor must have to deliver successfully?

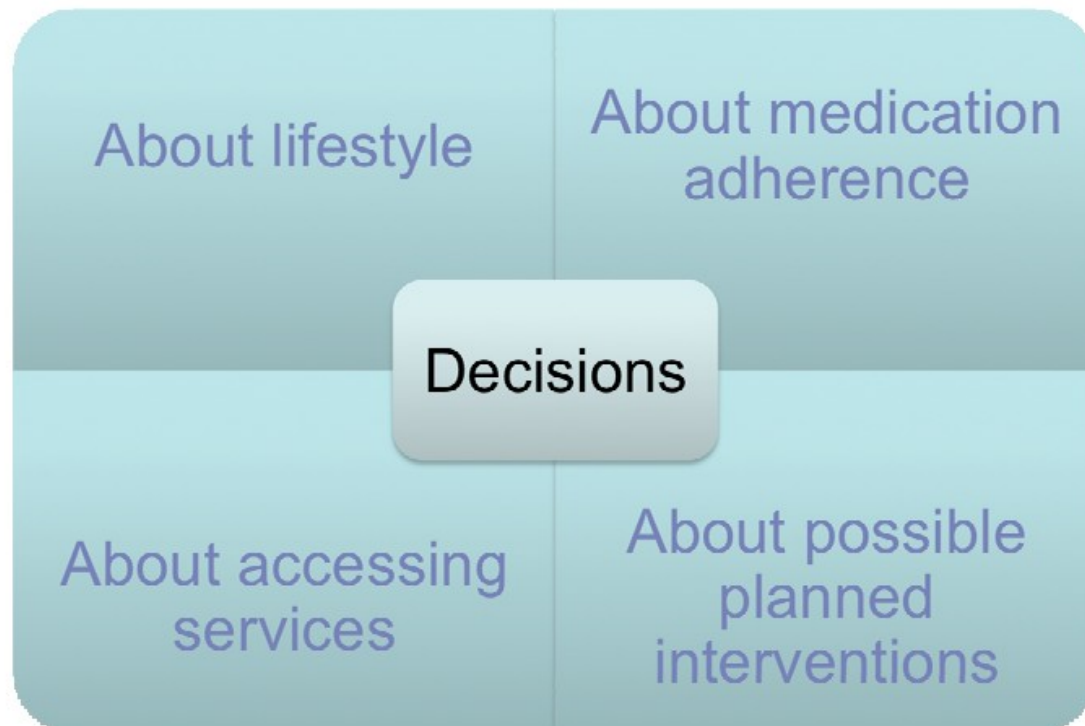


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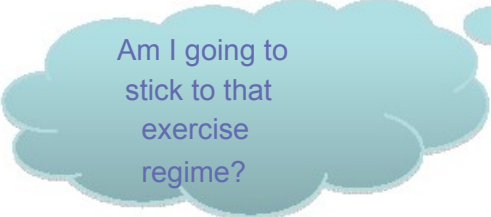
Yet people who live with  
LTCs are the ultimate  
decision makers and risk takers



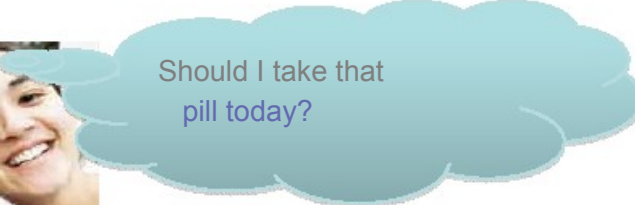
So it should be the job of the service to ensure that....




...People are supported to make informed and personally relevant decisions about their health



Am I going to stick to that exercise regime?



Should I take that pill today?



Do I really need that heart

## Information and behaviour



Information

Social pressures

Beliefs

Thoughts

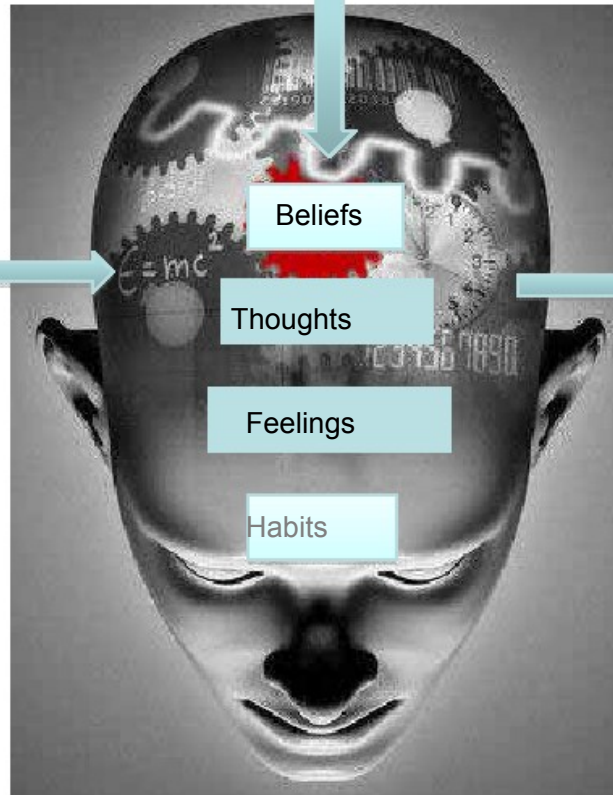
Feelings

Habits

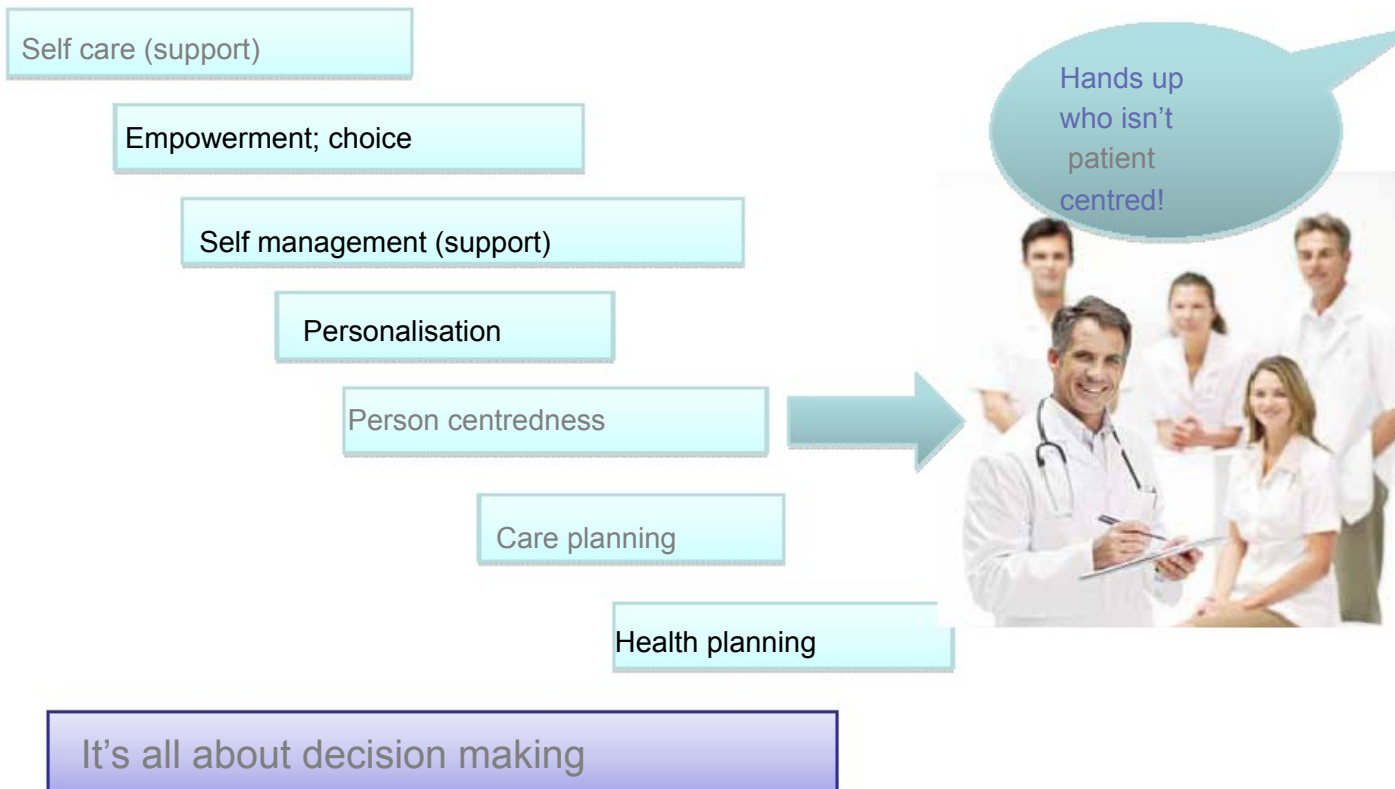
Behaviour

- Consistent
- Helpful
- Personally relevant

When did you last eat 5 a day?



## And on the subject of consistent information..



# Co-creating Health



A 3-year initiative 2007-2010 across 8 sites:

## Depression

Wandsworth Teaching Primary Care Trust & South West London and St George's Mental Health NHS

Torbay Care Trust & Devon Partnership Trust

## COPD

NHS Ayrshire and Arran

Cambridgeshire Primary Care Trust & Cambridge University Hospitals NHS Foundation Trust

## Musculo-skeletal pain

Calderdale and Kirklees Primary Care Trusts & Calderdale and Huddersfield NHS Foundation

Bristol Primary Care Trust & North Bristol NHS Trust

## Diabetes

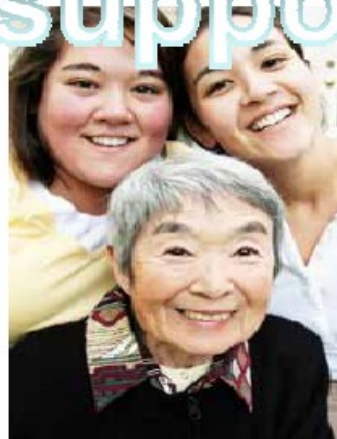
Southwark Health and Social Care & Guy's and St Thomas' NHS Foundation Trust

Islington and Haringey Primary Care Trusts & The Whittington NHS Hospital Trust

A programme that supports  
behaviour change

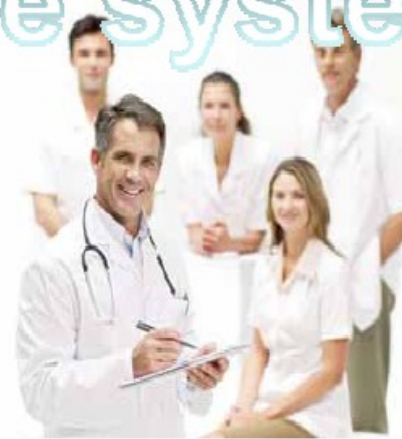


# A supportive system



A condition specific EPP

4,000 people with LTCs



A communication  
skills programme

500 clinicians

## Co-creating Health (CCH)



### 3 tools to support self management

Supported agenda setting

Supported goal setting

Follow-up on goals

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Activation. Hibbard et al 2003, 2006,

Hibbard Collins et al 2009

- Understanding that you have a role in managing your own health
- Feeling confident and capable in that role
- (Overlap with health literacy)

The clinical team's role...  
supporting people on their journey of activation



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## The Clinician ADP (care planning skills)

- Agenda setting
  - ‘what do you want to get out of today’s appointment?’ .... ‘what else?’
- Support autonomy/ activation
  - ‘what are you already doing to manage?’ ... ‘what have you considered?’
- Support goal setting and action planning
  - ‘what are you going to achieve before we next meet?’

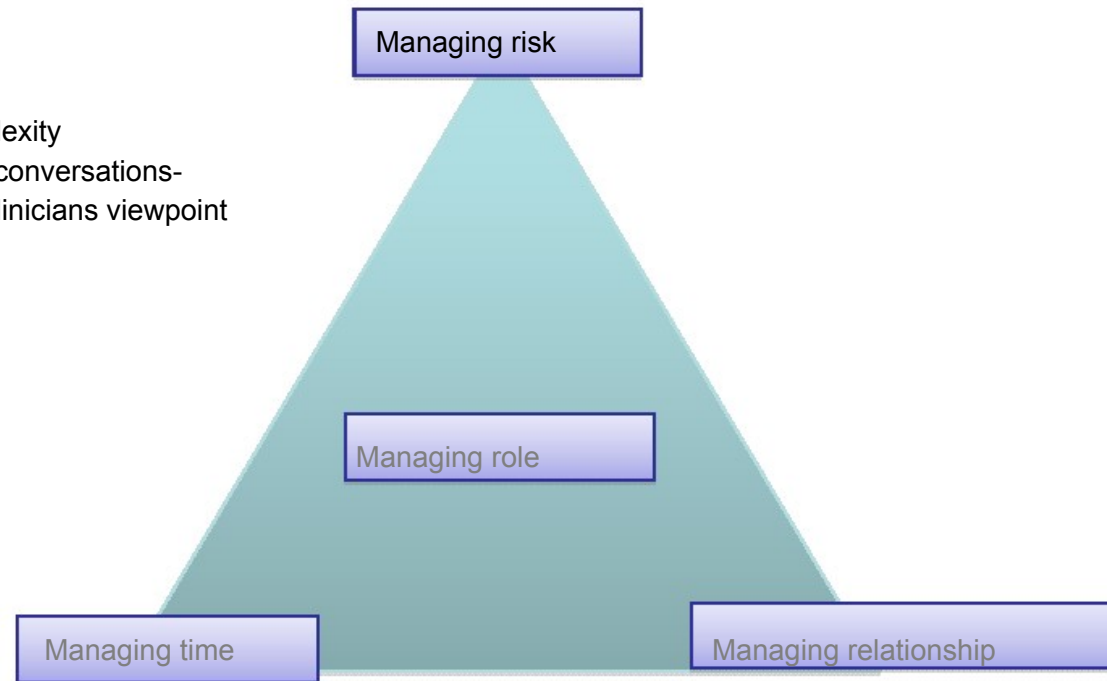


# What have we learned?

## Train teams



The complexity  
of clinical conversations-  
from the clinicians viewpoint



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What have we learned?

Employ QI principles

- Vision/evidence (the why)
- Metrics, metrics, metrics (the what)
- Rapid cycle feedback (the how)



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## The what

- Measure to improve
  - Process that supports agenda and goal setting
  - Patient reported outcomes of feeling supported and working in partnership (PPiC)
  - Patient reported outcomes of developing confidence (0-10 or PAM/abbr PAM)
  - Patient reported outcomes of QOL (PROMs)
  - Clinician reported outcomes (CROMs)



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## Early results from SMP

AT2  
AT3  
AT4



Outcome	BASELINE	FOLLOW UP
Patient Activation (0-100) ↑ = better	48	67*
Positive/active engagement in life (1-4) ↑ = better	2.8	3.0*
Emotional well-being (1-4) ↑ = better	2.2	2.4*
Constructive attitudes/approaches (1-4) ↑ = better	2.9	3.1*
Skill and technique acquisition (1-4) ↑ = better	2.9	3.1*

\*Statistically significant improvement

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## What else have we learned?

- These behaviours are not incentivised
- The system isn't overtly aligned (cf 18 weeks RTT)
- This is a formal project- it doesn't just happen....
- Projects stand or fall according to:
  - Clinical leadership (social modelling)
  - Project leadership (keeping on track)
  - Executive buy-in (supporting the vision)



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# Summary

- Self Management is the means by which people can develop confidence and skills to take control of the daily management of their health condition.
- The aim is to attain the greatest possible quality of life by **working with healthcare professionals and** to make the best use of all available resources including the patients own.



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## What participants say about EPP:

“I feel less isolated. It’s been great to be part of a group where everyone understands.”

“Makes you feel that you CAN do it”

“My life has taken a turn for the better since the Expert Patients Programme”

“I have learnt a lot from this course especially about exercise, action planning and better breathing”



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**Find out more:**

Visit our website

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or

Give us a call on

+44(0)207 922 7860



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