

Self Care Support

THE EVIDENCE PACK summary of work in progress (2005-07)

July 2007

Introduction

- This is a summary of work in progress on developing the evidence base on self care support
- Research trials predominantly show +ve outcomes, but sometimes there are unclear, neutral or -ve results
- This pack provides some examples of best results, and a few examples of what may appear to be neutral or negative results
- Longer paper in due course to explain the results
- Some examples of pilots being implemented

Best results examples

health and other outcomes

- increase in life expectancy
- better control over symptoms
- reduction in pain, anxiety and depression levels
- improvement in quality of life with greater independence
- days off work can reduce by 50%
- increase in social capital (more trainers, active citizens)
- implications for the care system
 - improved quality of consultations
 - visits to GPs can reduce by 40 to 69%
 - hospital admissions can reduce by up to 50%
 - hospital LOS can reduce
 - number of days in hospital may decrease by up to 80%
 - outpatient visits can reduce by 17 to 77%
 - A&E visits can reduce significantly
 - medication intake, e.g. steroids, reduced
 - medicine utilisation is improved by 30%

Contents of the Pack

- Findings of general public surveys on self care
- Impact of self care support by types of interventions
- Impact of self care support by health conditions
- The economic case
- Ongoing and planned research

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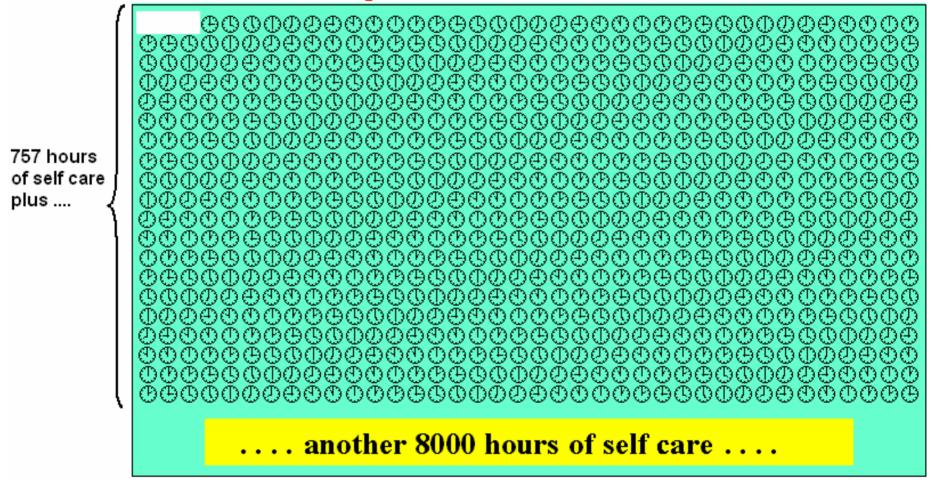
The public say they are active self carers

- 77% say they lead a healthy lifestyle
- 87% say they often treat minor ailment themselves
- 64% of those who have recently been in hospital say they often monitor their acute illness following discharge
- 82% of those who have a long term health condition, say they play an active role in caring for their condition themselves

Source: DH/MORI survey (2005) "Public views on self care"

③F THE 8760 H①URS IN ②NE YEAR ...

OOD A hours of professional care



HOUR BY HOUR CARE OF DIABETES

People want to do more self care

- More than 9 in 10 people were interested in being more active self carers
- > 75% said if they had guidance/support from a professional or peer they would feel far more confident about taking care of their own health
- More than half of people who had seen a care professional in previous 6 months said they had not often been encouraged to do self care
- A third said they had *never* been encouraged by the professionals to do self care

Source: DH/MORI survey (2005) "Public views on self care"

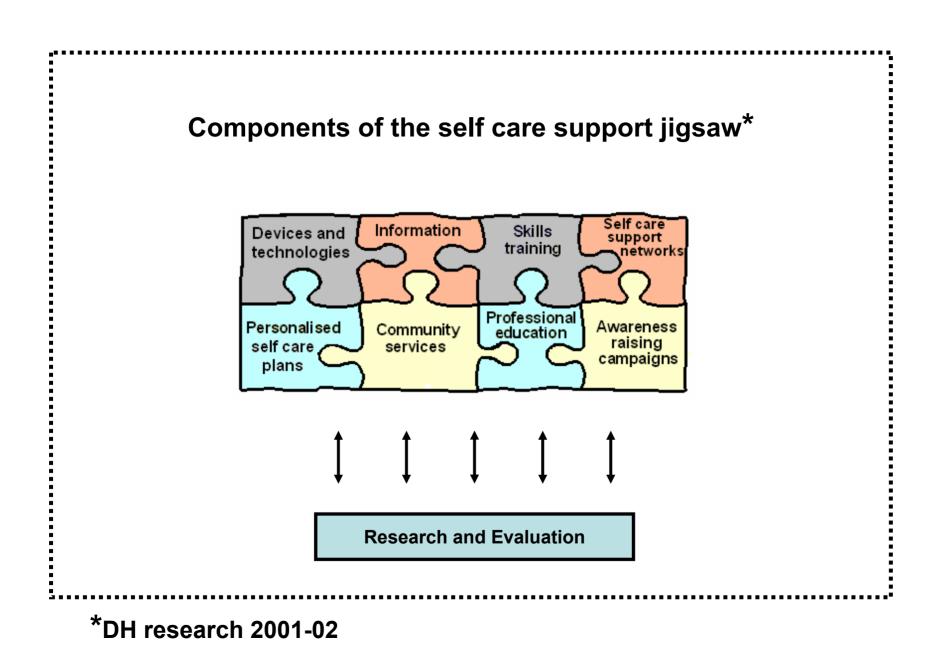
There is major potential for professionals to support self care

- 39% of GP time is spent dealing with patients suffering from self treatable minor ailments
- 75% of A&E attendances are for minor cases

Supporting self care can help professionals use their skills to best effect

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Self care plans: examples of best results

Study	Outcomes
Charlton et al (1990)	 reduction in visits to doctors
	decrease in use of medicines
Gillies et al (1996)	67% decrease in GP consultations
	 significant reduction in nights woken
	 significant reduction in days on steroids, reliever inhalers, and nebuliser use

Self care skills training and education: examples of best results

Study	Outcomes
Choy et al (1999)	69% reduction in GP visits
Fries J et al (1998)	 40% reduction in GP visits 9:1 benefit:cost ratio
Grossel E et al (2000)	 improved heath status improved self efficacy
Mannix et al (1999)	 improvement in disability due to headache reduction in OTC medicines
Montgomery et al (1994)	 24% reduction in visits to doctors 50% reduction in hospitalisation 12:1 savings:cost ratio
Oosterhuis & Klip (1997)	 significant improvement in duration of sleep, number of awakenings, quality of sleep, feeling of having rested well
Vickery et al (1988)	31% reduction in visits to doctors

Self care tools, devices and equipment: examples of best results

Study	Outcomes
Cherry J T et al (2002)	 32% reduction in inpatient admissions 34% in emergency admissions 44% in post discharge visits 49% in outpatient visits
Farmer AJ et al (2005a&b)	 number of people with good control over their condition quadrupled due to use of Medixine diabetes self monitoring
Levine PH (1973)	 home infusion leads to 76% decrease in outpatient visits
	 80% reduction in days in hospital
Ryan D et al (2005).	 74% using 'Think Positive Asthma System' including personalised self care plan found improvement in their ability to self care
Ryan P et al (2003)	• 30% increase in medicine intake
Timpka T et al (2004)	DiaBetNet interactive game for teenagers

Self care tools, devices and equipment: examples of best results

Study	Outcomes		
Celler BN et al (2002 a&b), (2003 a&b)	 up to 95% of people wish to continue using the self monitoring device GP satisfaction is also high at 89% 		
Guendelman S et al (2002)	 children using Health Buddy were significantly less likely to have any limitation in activity as a result of their asthma and significantly less likely to make urgent calls to hospital 		
Jarrett HD et al (2004)	pedometers are highly effective in increasing general levels of self care among users		
Jerant AA et al (2001)	reduction in readmission rate by 84%significantly fewer emergency visits		
Noel HD et al (2004)	 significant decrease in bed days emergency visits and A1C levels Veterion Monitor also found to improve the patients' cognitive status, medicine compliance, and the stability of their long term condition health care costs decreased by 58% 		
Tameside Council study on WristCare, a wrist-worn alarming device	 70% reduction in repeat falls 83% reduction in hospital bed days. 		
Tavris D et al (2004).	substantial reduction of morbidity and mortality wrt diabetes		
Walking the Way to Health: WHI Newsletter Issue 16, 2004. University College Worcester.	 95% of the PCTS found the pack effective in engaging front line staff 98% of health professionals said found pack useful for motivating people to take more exercise 93% of people said that having a step-o-meter increased their daily walking by an average of 1500 steps 		

Self care support networks: examples of best results

Study	Outcomes
Alemi F et al (1996)	participants in the bulletin board group made significantly fewer telephone calls and visits to health care clinics than participants in the face-to-face group
Becu M et al (1993)	decrease in depression and other psychological problems
Edmunson ED et al (1982)	 reduction in re-hospitalisation shorter LOS in hospital (7 days vs 25 days) reduction in use of MH services
Galanter M (1988)	 reduction in hospitalisation half of the group had been hospitalised before joining where as only 7% of recent members were hospitalised since joining
Gilden JL et al (1992)	 better diabetes knowledge, quality of life and depression scales less stress greater family involvement better glycemic control
Grimsmo A et al (1981)	peer led weight-loss groups in Norway; average loss of 14 to 15 pounds weight
Hinrichsen GA et al (1985)	 more positive outlook on life greater satisfaction with medical care reduced psychosomatic symptoms increased sense of mastery increased self esteem reduced feelings of shame and estrangement

Self care support networks: examples of best results

Study	Outcomes		
Humphreys K & R Moos (2001)	 fewer outpatient continuing care visits significantly less inpatient care 64% lower costs 		
Kingree JB et al (2000)	 increase in perceived personal strength changes in life philosophy improved interpersonal relations decrease in depression decrease in substance use 		
Kurtz LF (1988)	82% reported coping better49% reduction in hospital admission		
Liberman MN & NG Bliwise (1985)	 achievement of desired goals improvement in mental health indices, such as nervousness and depression 		
Maisiak R et al (1981)	• improvement in knowledge of cancer, ability to talk with others, family life, friendships, coping with disease, and following doctors' instructions		
McAuliffe, WE (1990)	 peer led self care style meeting and a weekend recreational activity led to significant reduction in relapse into addiction; increase in re-employment and reduced criminal behaviour 		
Minde K et al (1980)	 participants visited their infants in the hospital significantly more often, and touched, and talked to their infants more often during visits 		
Nash KB and KD Kramer (1993)	decrease in psychological symptoms and psychosocial interferences from the disease		
Peterson G et al (1985)	peer led group half as costly as the professional led group		

Self care support networks: examples of best results

Study	Outcomes
Pisani VD et al (1993)	increase in abstinence from alcohol use
Raiff NR (1984)	 no more anxiety about their health lowest levels of worry and highest levels of satisfaction with their health and life study recommends longer term involvement for best benefits
Simmons D (1992)	decrease in glycated haemoglobin levels
	increase in knowledge about diabetes
Solovitch S (2001)	 There are 17,000 health related websites in the world. Medline, a US government database of 11 million biomedical abstracts receives 120 million searches a year by the public. An estimated 60 million Americans (25%) get online health information; of these 41% say they use the information to make important health decisions
	parents know more about diseases than health care providers
	parents want to be partners
Spiegel D et al (1989)	 support group participants lived twice as long as controls starting from the time of receiving support (an average of 18 months longer)
Toseland RW et al (1989)	 significant increases in the size of support network increase in knowledge of community resources improvement in interpersonal skills and ability to deal with the problems of care giving improvement in relationships with care receivers decrease in pressing psychological problems

Further evidence on support networks**

- Patients no longer want information provided only by medical professionals; people find that exchange of experiences with other patients and ex-patients is the most reassuring and efficient way of getting support
- Communication and information technology provides opportunities to build community networks and helps individuals make self care decisions on issues relating to day to day lives
- Parenting websites like Netmums operate as an online community, with 275,000 users providing advice to prospective and current parents
- Mumsnet online site provides parenting information, along with reviews of products and services and claims around 10,000 posts and comments on an average day
- Patient Opinion enables people to share their experiences of healthcare, ranging from the temperature of the food served, to the professionalism of the nursing staff. This, in turn, provides independent feedback to the NHS and helps patients identify the 'best' healthcare providers for their specific needs, thereby empowering patient choice while helping to improve the NHS (www.patientopinion.org.uk)

Further evidence on support networks**

- Jooly's Joint online support network of over 10,000 people with Multiple Sclerosis provides a platform across the world for personalised reassurance and help in coping (www.joolysjoint.com)
- Ed Mayo, Chief Executive of the National Consumer Council : "The rise of the online communities is the story of our day. Information is what holds people together...."
- Tom Steinberg, founder and Director of mySociety : "... We are now at the start of a new era, where Government starts to learn how to support citizens' own ways of making, finding and re–using information online."

**from an independent review by Ed Mayo and Tom Steinberg – report commissioned by Cabinet Office Minister Hilary Armstrong http://www.cabinetoffice.gov.uk/newsroom/news_releases/2007/ stories/070607 power information.asp

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Growing evidence on self care for specific conditions

Various health conditions covered (see full research paper at www.dh.gov.uk/selfcare)

- Addiction
- Alzheimer's
- Asthma
- Behavioural disorder
- Bereavement
- Bi-polar disorder
- Breastfeeding
- Bronchiectasis
- Cancer
- Childbirth
- Chronic fatigue syndrome
- Claudication
- Constipation
- CHD
- COPD
- Cystic fibrosis

Growing evidence on self care for specific conditions

Various health conditions covered (see full research paper at www.dh.gov.uk/selfcare)

- CHD
- COPD
- Cystic fibrosis
- Depression
- Dermatological condition
- Diabetes
- Eating disorder
- Elderly
- Epilepsy
- Fibromyalgia
- HIV / AIDS
- Incontinence
- Insomnia
- Mental health
- Minor ailments
- MS

Growing evidence on self care for specific conditions

Various health conditions covered (see full research paper at www.dh.gov.uk/selfcare)

- Obesity
- Pain
- Panic disorder
- Parkinson's
- Rheumatoid arthritis
- Schizophrenia
- Sickle cell disease
- Stopping smoking
- Social phobia
- Somatisation disorder
- Spinal cord injury
- Stroke
- Weight loss
- Co-morbidities and generic interventions
- General health promotion

Condition specific interventions led by lay experts and/or professionals

Health condition	Ref	No. of studies	Intervention	Outcomes/benefits
Addiction (7,000 people with diagnosis of alcohol misuse or alcohol dependenœ)	Kownacki [1,1999]	10 RCTs 11 CCTs	Alcoholics anonymous (AA): • Training in communication skills • Group discussion • Senior abstinent peer-led group • Therapist led group	 AA yielded worse results Attending conventional AA meeting was worse than no intervention or alternative treatment
Alzheimer's (190 people aged65 and over)	Forbes [6, 1998]	7	Self care skills training, music, exercise, planned walking programme, simulated presence therapy (a personalised audiotape of a family member's telephone conversation about cherished memories), bright-light therapy, pet therapy, reality orientation, hand massage, white noise therapy. (Nurse led) 1. Social interaction (3 studies) 2. Aggressive, agitated, and disruptive behavior (1 study) 3. Self care ability (2 studies) 4. Wandering (1 study)	 Benefit in managing agitated or disruptive behaviour Significant improvement in treatment of conditions Patients eating by themselves more often Increase in the number of hours of productive sleep Floor grid pattern in front of a door is effective in limiting potentially dangerous exiting Camouflaging the doorknob are effective controls for reducing hazardous exiting Improvement in communicative function Improvement in social behaviours
Alzheimer's (2,200 people with dementia or cognitive impairment)	Cohen- Mansfield [7, 2001]	83	 Sensory interventions incl music (11 studies) Relaxation and massage (6 studies) White noise (2 studies) Sensory stimulation (4 studies) Social contact (2 studies) & pet visits (3 studies) Simulated presence videos (4 studies) Behaviour therapy (7 studies) Cognitive and stimulus control (9 studies) structured activities (3 studies) Outdoor walks and physical activities (2 studies) Wandering areas such as natural or enhanced environments (6 studies) 	 91% of the interventions had a positive impact 53% of all the studies reported a significant improvement in the health condition Note: Better matching and tailoring the interventions to the patients' needs and staff training result in greater benefits to the patients and their caregivers.

Bullet points marked in red show negative impact; those in blue show positive impact

Condition specific interventions led by lay experts and/or professionals

Asthma (2500 adults with asthma)	Gibson [8, 2004]	12 RCTs (Cochrane review)	 Self care education and skills training programmes, self care of trigger factors andside effects of medicines. Interactive interventions (5 RCTs) Non-interactive interventions (using print, audio, video, or electronic material) (3 RCTs) Combined interactive and non-interactive interventions (4 RCTs) 	 Reduction in A&E visits Improved perceived asthma symptoms No significant effects on hospitalisation, doctor visits, lung function, medicine use, number of days lost from normal activity.
Asthma (380 people with asthma)	Fleming [9, 2004]	12 RCTs (Cochrane review)	 Relaxation (autogenic training, hypnosis, progressive muscle relaxation) (8 RCTs) Tracheal noise biofeedback (1 RCT) CBT and rehabilitation (1 RCT) Behavioural and cognitive techniques (1 RCT) Hypnotic suggestions to improve symptom relief (1 RCT) 	Note: Sample sizes too small to draw adequate conclusions
Asthma (1400 children with asthma)	Haby (10, 2004)	8 RCTs (Cochrane review)	 Self care skills training interventions for children and/or parents delivered in A&E, hospital, home or in the community. Information giving Medicine control Action planning Self-monitoring 	 Some of the included trials demonstrated significant benefits, whereas others had a negative impact.
Asthma (3700 children with asthma)	Wolf [11, 2004]	26 RCTs and 6 CCTs (Cochrane review)	Self care skills training interventions intervention for children or adolescents and/or their parents • Prevention and self care of attacks • Social skills; role-playing • Problem solving • Delivered individually or in group sessions	 Moderate improvement in airflow Improvement in self-efficacy Reduction in days of school absence Reduction in days of restricted activity Reduction in the number of nights disturbed by asthma Benefits were greater for children with moderate-severe asthma, compared with those with mild-moderate asthma Note: Self care education programmes in children that are directed to the prevention and self care of asthma attacks should be incorporated into routine practice.

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Condition specific interventions led by lay experts and/or professionals

Robinson [20, 1999]	23 RCTs and CCTs	Cognitive behavioural interventions designed to assist children with increasing self-control: • Hyperactivity-impulsivity (11 studies) • Aggression (6 studies) • Hyperactivity-impulsivity and aggression (6 studies)	 89% of the studies had participants and experimental groups who experienced gains on both post-test and maintenance measures 88% of the participants on average experienced gains on receiving a cognitive intervention The results provide strong evidence for the efficacy of cognitive behavioural modification (CBM) in reducing the occurrence of hyperactive-impulsive and aggressive behaviours. Interventions including a cognitive component can significantly reduce inappropriate behavioural interventions reduce inappropriate and maladaptive behaviour
Huxley [21, 2000]	32 studies	Group and family therapies including CBT and interpersonal therapies: • Group therapy • Psycho social education • Interpersonal therapy • CBT • Family psychotherapy 13 controlled studies 13 pre-test post-test studies 6 anecdotal studies	 15% to 60% reduction in hospitalisations depending on intervention Reduction in hospital LOS from 16.8 to 3.6 weeks Increased adherence to medicines Improved economic status or vocational and social functioning Fewer and less severe episodes of mania and/or depression at 1 year of follow-up Patients reported a 'change for the better' Psychosocial benefits Participants had greater knowledge and more positive attitudes about treatments Fewer marital failures Better social functioning and family interactions Better global status, symptoms and role functioning Decrease in recurrence rates from 61% to 11% Improvement in knowledge of the illness, its treatment, and coping strategies Improvement in overall functioning Greater stability in daily routines Improvement in affective stability, overall functioning Longer time intervals before experiencing manic episodes Improvement in social and vocational functioning Improvement in social and vocational functioning Improvement in social and vocational functioning

Bullet points marked in blue show positive impact

Condition specific interventions led by lay experts and/or professionals

Bronchiec- tasis (50 participants)	Bradley [22, 2004]	2 RCTs (Cochrane review)	 Physical training using inspiratory muscle training Inspiratory muscle training (1 RCT) Inspiratory muscle training plus pulmonary rehabilitation (1 RCT) 	 Improvement in endurance exercise capacity, maximum inspiratory pressure, and quality of life
Cancer (2,060 participants with cancer)	Bottomley [23, 1997]	27 studies of which 13 RCTs	Information Problem solving Relaxation Social support	 Mental health benefits
Cancer (Adults with advanced cancer)	Allard [24, 2001]	33 studies of which 6 RCTs	Self care skills training interventions designed to improve cancer pain Role model training programmes for professionals involving physicians, nurses and pharmacists (90-minute programme to an extensive 40-hour programme) 15-minute counselling session for patients by an oncology nurse 3 educational home visits by a nurse who also delivers audiocassette tapes and a log book on medicine use	 Interventions directed at health professionals: Improvement in pain relief Lower mean pain intensity scores after the intervention was implemented Increase in activity by health professionals in implementing targeted cancer pain control activities in their own clinical setting Improvement in patient satisfaction with pain control Improvement in the nurses' knowledge about and attitudes towards cancer pain Improvement in adequate pain care with opioid prescription and parenteral administration Reduction in hospital readmission for uncontrolled pain Increase in compliance with recognised standards or guidelines of self care of cancer pain Improvement in patients' and caregivers knowledge about and attitudes towards cancer pain Improvement in patients' and caregivers knowledge about and attitudes towards cancer pain Improvement in patients' and caregivers knowledge about and attitudes towards cancer pain Improvement in pain relief Note: Methodological deficiencies of the studies, such as small sample sizes, uncontrolled study design and variable quality.

Bullet points marked in blue show positive impact

Condition specific interventions led by lay experts and/or professionals

CHD (Participants with hypertension)	Devine [33, 1995]	88 studies	 Skills training and education Behavioural monitoring [including self-monitoring of medicines/blood pressure, relaxation either with or without biofeedback, hypnosis or biofeedback alone) Relaxation, relaxation with biofeedback, psychosocial support with relaxation 	 Several forms of skills training or psycho-social interventions are effective in reducing blood pressure among adults with hypertension Education has a large effect on knowledge, and a positive effect on compliance with health care appointments Both monitoring and education have a positive effect on compliance with medicines
CHD (3,180 participants with coronary artery disease)	Linden [34, 1996]	23 RCTs	Psychosocial interventions (training in self care of stress)	 Reductions in psychological distress, systolic blood-pressure, heart rate, and cholesterol level 41% reduction in mortality 46% reduction in cardiac recurrence
CHD (7790 smokers were or aboutto be hospitalised)	Rigotti [35, 2004]	16 RCTs 1 CCT	Interventions for stopping smoking in hospitalised patients: (Majority of studies included patients with cardiac or pulmonary diagnoses.)	 Intensive behavioural interventions showed higher quit rates Studies incorporating nicotine replacement therapy [NRT] showed increased quit rates
CHD (10,357 patients, 9,803 with heart disease)	McAlister [36, 2001]	12 RCTs	Multidisciplinary programmes = patient education, appropriate consultation, exercise-based rehabilitation, social and psychological support for patients, self care of stress, counselling, management of risk factors, frequent telephone contact, coordination of home care CHD = angina, myocardial infarction, 'heart disease' congestive heart failure, patients undergoing coronary revascularisation	 One study reported a significant survival benefit Reduction in hospital admissions 5 out of 7 trials reported significant improvement in risk factors 5 out of 7 trials showed a significantly increased use of at least one of the prescription medicines [lipid-lowering agents and antiplatelet agents] 5 out of 8 trials showed improvement in quality of life Structured exercise led to greater survival rates Disease management programmes reduce admissions to hospital, and enhance quality of life or functional status in patients with CHD The programmes' impact on survival and recurrent infarctions, and their cost-effectiveness remain uncertain.
CHD (over 70,000 participants)	Bucher [37, 1999]	Diet 16 RCTs Statins 13 RCTs	Dietary interventions including low fat, olive oil, soya bean, diet drugs, and strict diet	 Cholesterol lowering diets were not associated with a reduction in coronary heart disease mortality, total mortality or non-coronary heart disease mortality. Note: Of the other interventions evaluated statins had the greatest overall effect.
CHD (1,110 participants)	Yucha [38, 2001]	21 RCTs	Biofeedback	 Biofeedback (with related cognitive therapy and relaxation training) showed a significantly greater reduction in both the systolic blood pressure and diastolic blood pressure

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Condition specific interventions led by lay experts and/or professionals

CHD (3927 people with CHD)	Philbin [44, 1999]	2 RCTs 5 studies with patients used as their own control	Multi-disciplinary intervention: Patient self care skills training and education Lifestyle changes Exercise Home visits Nurse-managers directing education Nurse-managers utilising weekly mailings and phone calls with high technology home monitoring	 Improvement in functional status, Improvement in aerobic capacity Improvement in patient satisfaction Improvement in quality of life measures 50% to 85% reduction in the risk of hospital admission Decrease in hospital admissions Reduction in subspecialty dinic visits Comprehensive multidisciplinary programmes may lower medical costs Increase in general practice visits and hospital re-admissions
CHD (9081 participants with CHD)	Dusseldorp [46, 1999]	28 RCTs 9 quasi randmised studies	 Self care support for stress Self care skills training Exercise training 	 Decrease in blood pressure Reduction in cholesterol Reduction in body weight Increase in those stopping smoking 34% reduction in cardiac mortality 29% reduction in the recurrence of MI Improvement in physical exercise and eating habits There was no evidence that the interventions reduced anxiety or depression.
CHD (7683 people with CHD)	Joliffe [46, 2004]	32 RCTs (Cochrane review)	Cardiac rehabilitation involving: • Exercise training • Psychosocial and / or educational interventions	 Statistically significant reduction in all cause mortality Cardiac mortality significantly reduced by 26 - 31% Significant net reduction in total cholesterol and LDL
CHD (577 participants preparing to undergo cardiac surgery)	Shuldham [47, 2001]	7 studies 2 RCTs 5 CCTs	Self care skills training and education including: • Booklets • Slide shows • Videos • Telephone or other containing information on tests, procedures, anatomy, possible complications, physiotherapy, etc	 Significant positive effects in respect of well-being and knowledge Shortened length of stay in hospital There was limited evidence to suggest that pre-operative education benefits the patients' recovery from CABG.

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Condition specific interventions led by lay experts and/or professionals

COPD (3,642 adults with COPD)	Devine [48, 1996]	65 studies 22 RCTs 13 CCTs 30 pre-test post-test design	 Pulmonary rehabilitation through large muscle exercise and education often in combination with breathing exercises, relaxation, psychosocial support or vocational training Self care skills training and education on COPD, coping with stress, breathing techniques, and use of medicines Guided imagery, cognitive counselling and frontalis muscle biofeedback 	Pulmonary rehabilitation, self care skills training, education and relaxation had statistically-significant beneficial effects on: • psychological well-being • endurance • functional status • oxygen uptake • dyspnea • adherence to treatment • significant beneficial effect on the accuracy of performing inhaler skills • small or medium-sized effect on health care utilisation and on adherence to treatment regimen • reduction in psychological distress and dyspnea through relaxation • improvement in psychological well-being through relaxation • comprehensive pulmonary rehabilitation programmes have been shown to improve multiple measures of functioning and well-being of adults with COPD • psychomotor skills [e.g. inhaler use) improved through education
COPD (324 participants with COPD)	Rose [49, 2002]	6 RCTs	Psychological interventions including: • education and self care of stress, with and without exercise • pulmonary rehabilitation • relaxation (taped) • analytic, supportive or nurse psychotherapy • rehabilitation • counselling	 Relaxation techniques have a beneficial impact Exercise showed effect sizes ranging from 0.43 to 0.85 Secondary outcome measures reported were impacts on breathlessness, disability and quality of life The findings were variable.
COPD (279 people with COPD)	McBride (50, 1999)	3 RCTs 1 case series	 Rehabilitation including physical and exercise therapy Community based pulmonary rehabilitation run by physiotherapists Hospital outpatient based pulmonary rehabilitation Bicycle exercise training programme Education and supervised exercise 	 Physiological, psychological and QoL Improvements were observed and maintained for 6 months Exercise had a moderate effect on respiratory function and significant protective effect against post-operative respiratory complications Hospital outpatient-based pulmonary rehabilitation programmes are effective in improving quality of life for patients for up to 18 months Benefits also accrue to their carers
COPD (877 patients with COPD)	Lacasse [51, 1997]	22 RCTs	 Exercise regimen and breathing exercises Self care skills training and education Psychological intervention 	 Relaxation shown to relieve dyspnea in the short term Behavioural modification techniques improve exercise tolerance and HRQL Psychosocial support reduce breathlessness and promote patient compliance Some gains from breathing exercises such as those used in yoga or tai chi People with mild or moderate COPD could achieve maximal physiological training by establishing individual training intensities at or above the anaerobic threshold. However, there was no evidence that this influenced health outcomes.

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Condition specific interventions led by lay experts and/or professionals

Depression (636 people with anxiety, depression, stress and/or tiredness)	Bower [56, 2001]	8 RCTs	 Self-help (intervention administered through booklets, text, audiotape, videotape or computer text, or through group meetings or individual exercises such as 'therapeutic writing') Written material plus telephone contact with nurse 	 Significant advantages associated with self care on at least one measure Self care packages likely to offer clinical advantages
Depression (800 people with depression)	Cuijpers [57, 1998]	14 studies 12 RCTs 2 CCTs	Psychological outreach programmes, problem-solving therapy, CBT, Group therapy, psychodynamic therapy, supportive therapy, social contact, bibliotherapy, and reminiscence.	 Note: Most of the selected studies had small sample sizes, and hardly any placebo or no treatment control groups were used Despite these limitations, this meta-analysis indicated that the effects of interventions in which depressed elderly are actively recruited from the community are large
Depression (295 adolescents with depression)	Marcotte [58, 1997]	7 studies with a control group	 Role play Relaxation training CBT for adolescents with and without parents Self-modeling Social skills Therapeutic support Rational-emotive therapy Structured learning therapy 	 The effect size at post-test ranged from 0.41 to 1.70 [small to large effect size) and the effect size at follow-up ranged from 0.60 to 1.69 [medium to large effect size). These results suggest that the intervention groups improved more than the controls All short-term group interventions were effective for both early and late adolescents, with improvement being maintained at follow-up
Depression (272 people with unipolar depression)	Cuijpers [59, 1997]	6 studies with waiting list controls	 Cognitive behavioral bibliotherapy Social skills training Cognitive bibliotherapy (1 study) 	 Bibliotherapy was found to be an effective treatment modality in unipolar depression Note: All participants were recruited through announcements in the media, therefore results may not be generalised to patients of mental health institutions??
Depression (926 people with post-natal depression)	Boath [60, 2001]	29 studies 9 RCTs 1 CCT 2 cohort studies 17 case studies or descrptive reports	Combined psychological and psychodynamic approaches, i.e. interactional/problem resolution, CBT, group psychotherapy, interpersonal psychotherapy, psychodynamic psychotherapy, interactional guidance, psychotherapy on mother-infant interaction, counselling, listening visits, relaxation, social support group, group by mail, exercise, massage, support group with and without partner, bright light therapy	 Lower rates of depression for the active intervention 31-55% fewer people depressed in intervention group Interpersonal psychotherapy decreases BDI and HDRS scores CBT leads to significant improvement in mood [EPDS, BDI, POMS), Counselling leads to reduction in psychiatric morbidity Massage sessions reduced anxiety levels and stress hormone levels at 10 days Support group that included partners significantly decreased depression rates after 7 sessions Note: The methodological flaws included: lack of placebo control; extremely small sample size; high drop-out rates, etc etc. The
				methodological limitations mean that the there is little good evidence available on which to make clear recommendations.

Bullet points in blue show positive impact

Condition specific interventions led by lay experts and/or professionals

Dermato- logical condition (Participants with atopic eczema or atopic dermatitis)	Hoare [64, 2000]	283 RCTs of atopic eczema	Psychological approaches, ultraviolet light therapy, maternal allergen avoidance, Chinese herbs, dietary restriction, homeopathy, house dust mite reduction, massage therapy, hypnotherapy, evening primrose oil, emollients, topical coal tar, topical doxepin, the avoidance of enzyme-based washing powders, cotton versus synthetic clothing, biofeedback, and antiseptic bath additives in prevention or treatment of atopic eczema	 Psychological approaches and ultraviolet light therapy found to be beneficial Evidence insufficient to support any clear clinical benefit with regards to maternal allergen avoidance for disease prevention, Chinese herbs, dietary restriction, homeopathy, house dust mite reduction, massage therapy, evening primrose oil, emollients, topical coal tar, avoidance of enzyme-based washing powders, use of cotton clothing, biofeedback, and antiseptic bath additives.
Diabetes (11,415 adults with type 2 diabetes)	Norris [65, 2001]	72 RCTs	Individual or group-based self care skills training and educational interventions in different settings, delivered by different provider types, involving different media: knowledge and information giving lifestyle interventions self care skills training coping skills interventions	 Positive effects of self care skills training on knowledge, frequency and accuracy of self-monitoring of blood glucose, self-reported dietary habits, and glycaemic control Some improvement in glycaemic control Self care skills training and educational interventions that involved patient collaboration may be more effective than didactic interventions in improving glycaemic control, weight and lipid profiles Evidence supports the effectiveness of self care skills training in type 2 diabetes, particularly in the short term
Diabetes (1,322 people with diabetes, or at risk of developing diabetes in ethnic minority, low-literacy and low-literacy and low-income groups, and older adults with a variety of long term conditions)		10 studies 6 RCTs 4 CCTs	Diabetes self care educational interventions that aimed to teach diabetes self care. (e.g. blood glucose monitoring, glycaemic control, dietary habits and exercise)	 Significant reduction in weight Significant reductions in one or more measures of blood glucose control Significant positive changes in dietary patterns Significant positive changes in physical activity Significant favourable psychosocial outcomes Significant long-term improvements on various measures of blood glucose control Significant improvements in long-term dietary and/or physical activity outcomes Note: This meta-analysis provides useful ideas on how to effectively deliver interventions in ethnic minority, low literacy, low income groups, for example, use of proactive phone calls, touch-screen computerassisted information delivery, and practice redesign that incorporate self care support and peer support into primary care by scheduling diabetes patients for primary care visits at the same time. Also the analysis notes that interventions in community settings for underserved populations should explicitly address socio-contextual issues in the patients' lives.
Diabetes (Participants with diabetes)	Valk [67, 2004]	8 RCTs (Cochrane review)	Educational programmes for foot care among people with diabetes.	 Significant reductions in the incidence of ulcers in high-risk patients and the rate of amputation after 1 year Education significantly improved knowledge regarding foot care Reduction in the number of serious foot lesions at one year follow- up and improved foot care behaviour

Bullet points marked in red show uncertain impact; those in blue show positive impact

Condition specific interventions led by lay experts and/or professionals

Diabetes (734 adults and children with diabetes Type 1 or 2, and women with gestational diabetes mellitus (GDM) or diabetes in pregnancy)	Coster [73, 2000]	8 RCTs	 Self-monitoring (blood glucose and urine glucose) Patient education Feedback of glycated haemoglobin results Calorie-controlled diet Weight-control programme Self-monitoring in diabetes mellitus during pregnancy 	A narrative summary of the findings concluded that women with Type 1 diabetes can achieve blood glucose control as good as that achieved by patients who receive intensive control in hospital, and hospital admission was less for women managed athome with SMBG. Maternal and foetal outcomes may be as good with SMBG athome, and this approach was preferred by the patients. In GDM, the monitoring of blood glucose after meals, rather than before, may lead to better metabolic control and foetal outcomes. Note: - Self-monitoring in Type 2 diabetes: All of the trials included too few patients. - Self-monitoring in Type 1 diabetes mellitus: poor conduct and reporting. - GDM and diabetes in pregnancy: poor conduct and reporting.
Diabetes (1,800 people with diabetes)	Brown [74, 1996]	89 studies	Behavioural therapy, exercise and diet.	 Diet alone had the largest statistically-significant impact on weight loss and metabolic control. Diets significantly reduced fasting blood sugar levels. Behavioural therapy programmes have a significant effect on weight loss and metabolic control. Exercise alone produced less change in weight loss and metabolic control than diet alone. Behavioural therapy plus diet plus exercise had a statistically significant impact on both weight loss and metabolic control. However, this effect was not as large as for diet alone. The effects were smaller for individuals over the age of 55 years.
Diabetes (outpatients (82%) and inpatients (18%) with diabetes)	Balas [75, 1996]	100 RCTs	Computerised information services, targeted at providers or patients, included: provider prompt or reminder; computer-assisted treatment planner; provider feedback; computerised medical record and information access; computer-assisted interactive patient education; patient prompt or reminder.	 Provider prompt or reminder, computer-assisted treatment planner, interactive patient education or therapy, and patient prompt or reminder were significantly successful interventions. Physician and patient reminder, treatment planner, and patient education are four generic information interventions can make a significant difference in family medicine.
Diabetes (502 adults and 259 children with IDDM or NIDDM diabetes)	Balas [76, 1998]	15 RCTs	Computerized interventions included the following: glucometer data transmission; network data transmission; computerised diet assessment; computerised diet counselling	 Significant benefit for use of computer was reported in 80% of the trials Significant reduction in HbA1c level Significant reduction in blood glucose levels Significant reduction in number of hypoglycaemic episodes Patient computer interaction appears to be a valuable addition in the care of people with diabetes. Considering the need to enhance patient participation in the care of people with long-term conditions, initial evidence indicates computers can play a significant role in the future.

Bullet points in blue show positive impact

Contents of the Pack

- Findings of public surveys on self care
- Impact of self care support by types of interventions
- Impact of self care support by health conditions
- The economic case
- Ongoing and planned research

Few studies highlighting cost-effectiveness (c-e) and/or benefit:cost ratio

Study	Condition / intervention	Ratio
Fries J et al (1998)	High risk groups	9:1
Grossel E (2000)	LTC	22:1
Kennedy AP et al (2007)	EPP	с-е
Kennedy AP et al (2004)	IBD	с-е
Leigh P et al (1992)	Retiree health promotion	5:1
Liu CF (2003)	Depression	с-е
Montgomery et al (1994)	Parkinson's	12:1
Moore J et al (1980)	Self care book	9:1
Oosterhuis (1997)	Insomnia	1.05:1
Vickery et al (1988)	Medicare population	2:1
Vickery et al (1983)	Minor illness	3:1
Von Korff M et al (1998)	Depression	с-е

Cost and benefits of supporting self care (see also Wanless Report)

Weighted average cost per user = £100

Corresponding benefit = £200 (through savings from reduction in use of services etc)

Additional benefits include:

- better communication between patients/users and professionals
- better use of information
- reduction in pain
- reduction in disabilities
- increase in self confidence
- reduction in anxiety and depression
- reduction in days off work
- improvement in quality of life
- increase in life expectancy
- increase in social capital .

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Self care skills training programmes research

- EPP Online
- DAFNE for Type 1 diabetes
- DESMOND for Type 2 diabetes
- Persistent Pain Programme
- Staying well with asthma
- Challenging arthritis
- Caring for people with HIV AIDS
- Looking After Me (programme for carers)
- Supporting Parents Programme
- Self care skills training for children & young

Emerging Evaluation & Monitoring

- Evaluation of NHS Direct family (SCHARR)
- Expert Patients Programme RCT, qualitative and economic studies (NPCRDCs – York and Manchester)
- WiPP Self Care Support for People and Self Care Training for Professionals (Leeds Met)

Expert Patients Programme RCT findings:

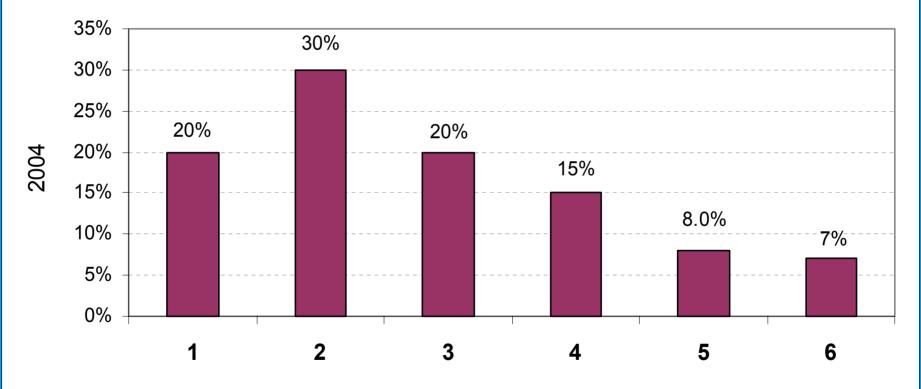
- significantly greater self efficacy
- significantly greater energy levels
- significantly greater health related quality of life
- 50% reduction in use of hospital services
- reduction in costs: 70% probability that EPP is cost-effective
- EPP a useful addition to current services in the care of people with long term conditions

Expert Patients Programme Internal Monitoring findings:

- significant increase in confidence levels that they would not let the symptom interfere with their lives
- significant decrease in perceived intensity of symptoms
- 7 % reduction in GP consultations
- 10% reduction in outpatient visits
- 16% reduction in A&E attendances

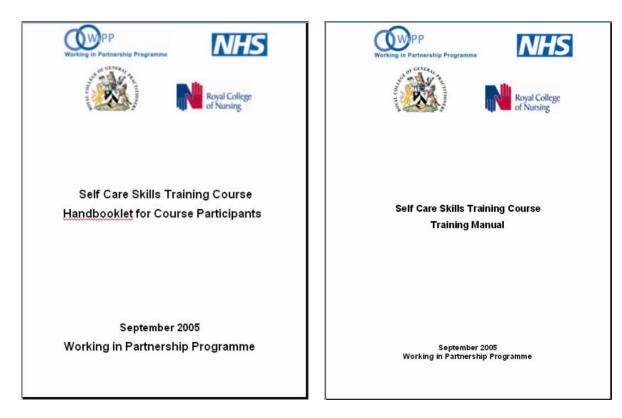
Emerging data from Internal Monitoring

Number of Long Term Conditions



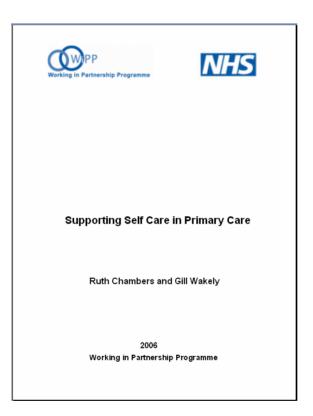
Expert Patients Programme

Working in Partnership Programme pilots



Self care support for people (results 2008) •Airedale PCT •South Tyneside PCT •Oldham PCT

Working in Partnership Programme pilots



Training for Professionals (results 2008) •Airedale PCT •Central Cheshire PCT •Lambeth PCT

Care of People with Long Term Conditions research

- 'Life Checks' pilots for people at key life stages
- Self care support in case management of intensive users and people with complex co-morbidities
- Future research on Expert Patients Programme as courses per year increase from 12,000 to 100,000
- 16 pilots of the Integrated Service Improvement Programme (ISIP) which will help transform clinical services around the patient.

Examples of pilots:

- 1. In Calderdale and Huddersfield, provide enhaced support for self care for people with rheumatoid arthritis
- 2. In Central Nottinghamshire, delivering a community based approach for people with diabetes including structured self care skills training and improved communication links
- 3. In Tower Hamlets, delivering self care skills training for people with long term conditions and their carers

See www.isip.nhs.uk

Copying letters an effective way of keeping patients up to date for enhanced self care (research on 12 pilots)

- Bolton Patients Council for Mental Health Service Users
- George Elliot Hospital NHS Trust introducing the Infoflex system
 which has ability to generate clinical letters for cancer patients
- A study of patient's views in the anxiety clinic at Birmingham Dental Hospital
- Copying letters to dementia patients and their carers from ethnic minorities in Wolverhampton
- Great Ormond Street Hospital for Children and Carers of Children
- Gulson Hospital for Children and Carers of Children
- Wolverhampton PCT for Carers of Children with Learning Disability
- Ealing PCT and Ealing Hospital Trust for non-English speaking patients
- Street Lane GP Practice
- Bury Knowle Health Centre and the Department of Public Health Letters Online

Information Prescriptions an effective way of providing self care information (research on 20 pilots 2008 onwards)

- 20 pilot sites for people with long term care needs
- Focusing on a diverse range of long term conditions
- Pilots to identify sources that people should be signposted to
- Generate a template to determine how a personalised information prescription is created for a specific care pathway
- Establishing directories of content
- Determine how patients can choose what is best for them
- Ensure that the process is inclusive
- Pilots based in a range of health and social care organisations: PCTs, hospitals, MH trusts, LAs, GP surgeries and the voluntary and community sector

Information Prescriptions an effective way of providing self care information (research on 20 pilots 2008 onwards)

- 1. County Durham PCT Macmillan Cancer Information and Support Centre
- 2. University Hospitals Birmingham NHS Foundation Trust
- 3. Mid Trent Cancer Network Nottingham
- 4. Royal Marsden NHS Foundation Trust
- 5. Doncaster PCT
- 6. South Staffordshire healthcare NHS foundation trust
- 7. Cambridgeshire and Peterborough Mental Health Partnership NHS Trust
- 8. Suffolk County Council
- 9. Isle of Wight Council
- 10. Heart of England NHS Foundation Trust
- 11. Diabetes UK and Hammersmith and Fulham PCT
- 12. Manchester City Council and Manchester PCT
- 13. Northumbria Healthcare NHS Foundation Trust and Parkinson's Disease Society
- 14. RNIB and Yorkshire and the Humber Strategic Health Authority
- 15. Oxfordshire County Council working with Oxford Centre for Deaf and Hard of Hearing
- 16. Leeds Mental Health Trust
- 17. Evelina Childrens Hospital
- 18. Oxleas NHS foundation trust
- 19. Darlington PCT
- 20. South Essex Partnership NHS Foundation Trust

Whole System Demonstrator Programme

- Assistive technology, telehealth and telecare to support self care for people with complex health and social care needs
- Improve care for frail older people
- Inform people fully about their condition so they are better able to care for it
- Provide health and social care commissioners with the right incentives to deliver better care for those with complex needs

Whole System Demonstrator Programme

- 3 Demonstrator sites: Newham, Kent and Cornwall
- Collectively serve a resident population of 1 million
- Variety of demographic and geographical contexts
- Run for a minimum of two years
- Subject to rigorous real time evaluation process
- On a scale significantly greater than anything undertaken in England, with over 7000 telecare/telehealth installations over the 2 year period across the three sites

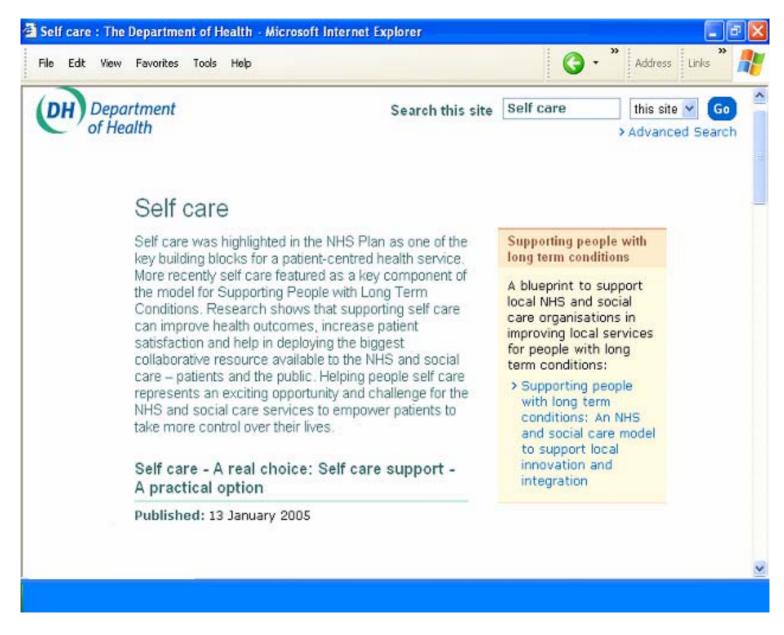
Focuss on two user groups

- People of any age who are at risk of hospital admission due to at least one of the following conditions: CHD, COPD or type II diabetes
- Frail older people at risk of hospital admission, who have complex health and social care needs

NHS SDO RESEARCH: results 2009

- 1. Evaluating self care support for children and young people with long term conditions (School of Nursing, Midwifery and Social Work)
- 2. Self care support for older adults: availability, impact and potential of locally based services and resources (Picker Institute)
- 3. Understanding the barriers and facilitators of effective implementation of self care support in MH Trusts (St George's, University of London)
- 4. Self Care Support within Case Management (Personal Social Services Research Unit)
- 5. Role of commissioning in supporting self care (University of Birmingham)

Self care research and references at www.dh.gov.uk/selfcare



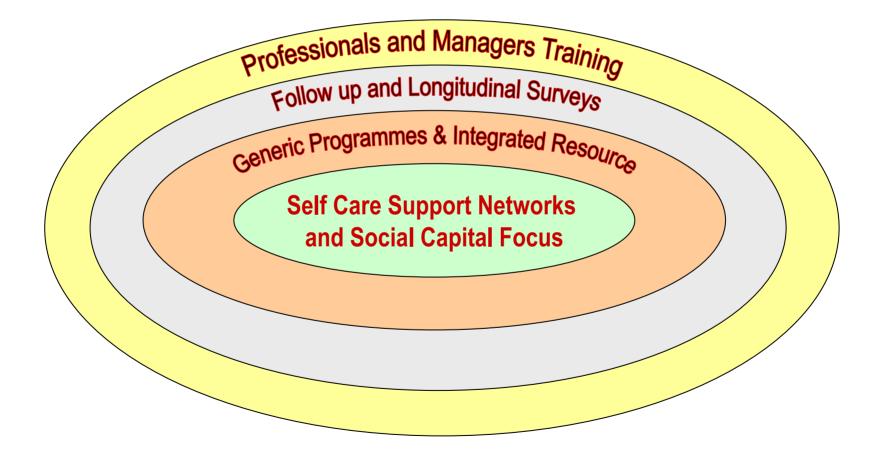
WISH LIST

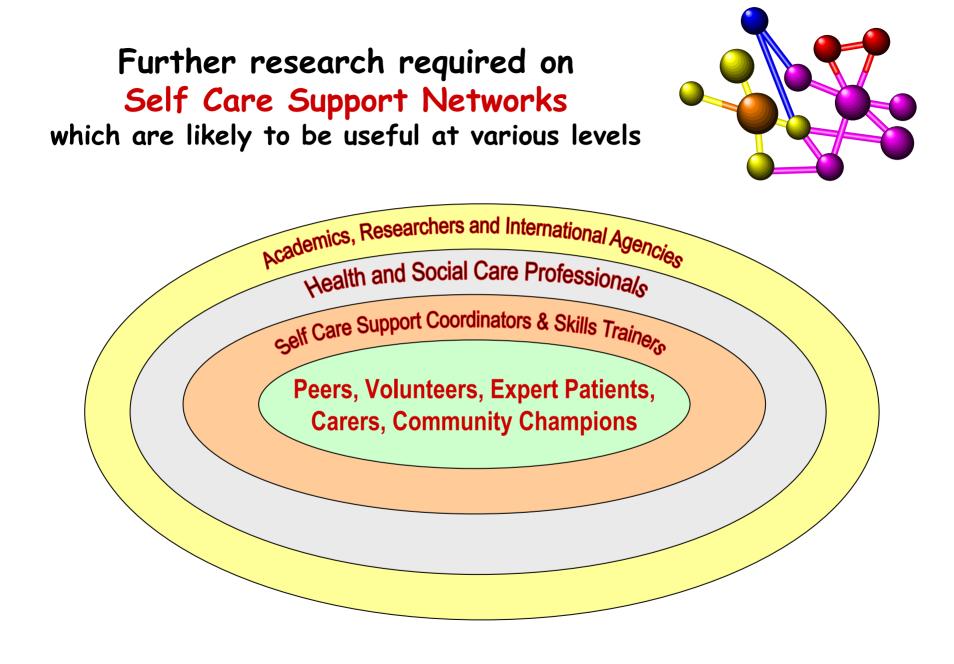
there are other areas where we need more evidence: see areas marked in red in the next 3 slides...

Barriers, obstacles and risks

Gaps in professional skills and education	Multi-format information not always available	s Little Iongitudinal	Professionals cometimes unwilling to empower and enable patients
Lack of universal access to self care	Self care support resource not integrated	research available	Resource constraint
support such as IT	Self care may be seen as a form of rationing	Concern over risks	Measurement of NHS
Professional worry about demand stimulation	Usefulness of peer support not sufficiently recognised	User friendly equipment no always available	t performance focused on conventional services and concept

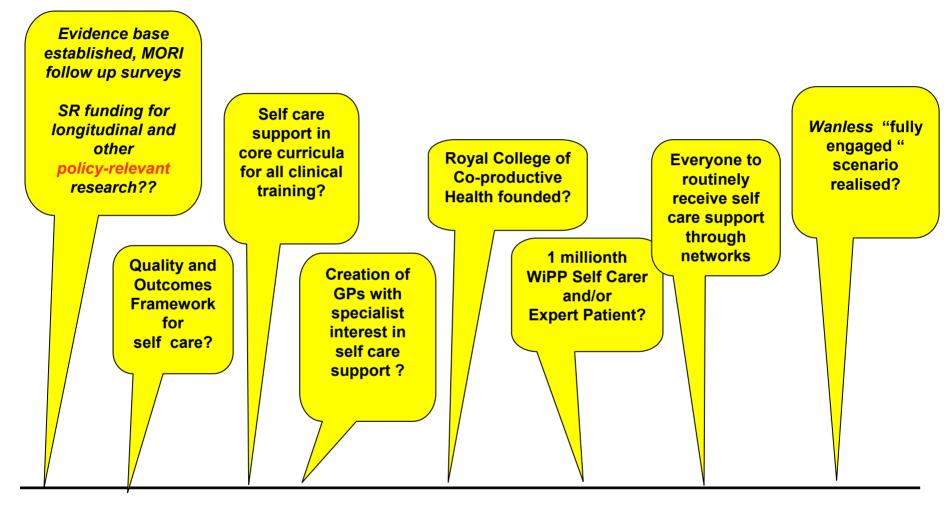
Areas requiring further research





ANOTHER WISH LIST??

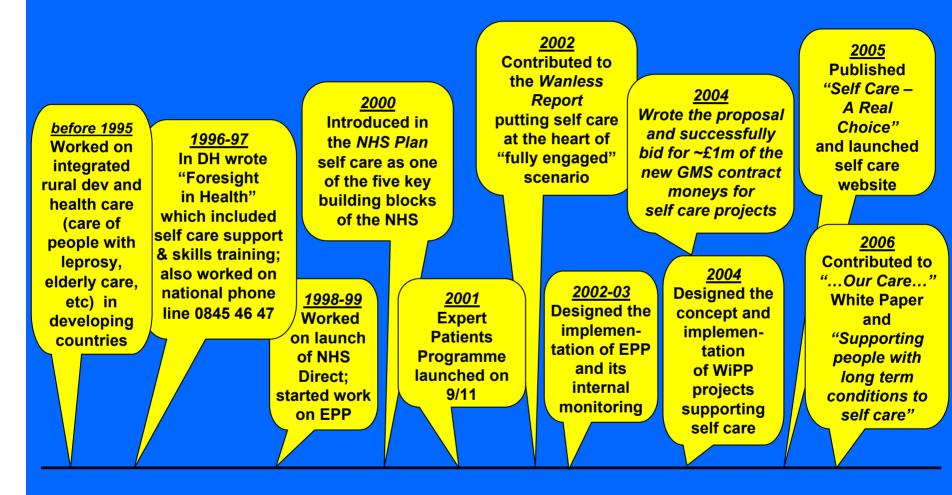
Self Care Support: the next decade?



Final contribution to the growing work on Self Care Support

This is likely to be my final contribution to the growing work on self care support in the NHS, social care and DH before moving on to other areas of work.

Recap: some of my contributions to developing Self Care Support in NHS and wider world



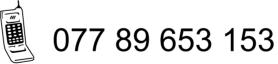
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2001

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Ayesha Dost



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Send your comments to selfcare@dh.gsi.gov.uk