APPENDIX 1: Self care: literature review and policy context

1.1 Defining self-care

Self-care has been characterised as the basic level of health care in all societies (Segall & Goldstein 1989), however, there is currently no commonly accepted definition of self-care either within the literature or within and between PCTs (Department Of Health 2005a).

Orem's theory of self-care (Orem 1995) postulates that self-care behaviours are learnt and that a person performs self-care activities to maintain life, health and well being. Whilst adults are deemed to have the ability to care for themselves children, the ill and the disabled are said to require support with undertaking self care activities. Whilst Orem has been instrumental in the development and understanding of the term self care, there have been numerous other definitions formed from a number of different disciplines, encompassing differing concepts of what self care entails, differing defining levels of involvement and how self care is achieved (Becker et al 2004). Self care has emerged as a multidimensional concept constructed from a wide array of perspectives. Alongside such developments the World Health Organisation (WHO) has formed a broad definition of self care as "what people do for themselves to establish and maintain health, prevent and deal with illness." (www.who.int).

There is a question of whether self-care is seen as a contrast or a compliment to health service usage (Dean 1981). Researchers have tended to assume that the success of everyday self-care decisions can be measured simply in terms of how well they comply with a prescribed regime of health behaviour or the advice of health practitioners, however, from a patient participation perspective, those with chronic illness who rely unquestionably on the advice of practitioners are seen as suffering from a self-care deficit (Paterson et al 2001). There is evidence that those who tend to visit the doctor more and self-care less perceive themselves as less healthy (Anderson et al 1977).

1.2 Self care and UK health policy

It is only relatively recently that self care has become a feature of health policy within the UK. In 1999 the Department of Health established the Expert Patients Task force, a strategy which was born out of the 1999 White Paper *Saving Lives:*

Our Healthier Nation (DH 1999). The key aim of the taskforce was to design a programme focused around lay-led self management strategies, which would enable people who suffer from chronic illness to “maintain their health and improve their quality of life”. What emerged was the Expert Patients Programme (EPP), an intervention based upon the Chronic Disease Self-management Programme developed in the USA (NPCRDC 2006). Unlike the Chronic Disease Self-management Programme the EPP is a generic programme, not tailored to one specific condition, therefore with the ability to engage with a greater number of people. At the core of the EPP is a 6 week training course delivered by people who have experienced and managed their own long term conditions.

In 2000 the NHS Plan confirmed the commitment to self care on the national health agenda, placing self care as one if its five key service elements (Department of Health 2000a). The plan asserted that the frontline for healthcare is in the home, rather than traditionally defined healthcare settings. The introduction of NHS Direct, with its phone line and website were predicted to become a hub for enabling people to look after themselves. Alongside NHS Direct it predicted the development of digital television channels dedicated to healthcare and the introduction of NHSplus.

The publication of *Pharmacy in the Future - Implementing the new NHS plan (*Department of Health 2000b*)* positioned the pharmacist on the front line of the self care strategy. The report set down three challenges for pharmacists, firstly ensuring that patients are able to receive access to medicines and advice as easily as possible. Secondly pharmacists would be required to provide more support for patients using medicines and finally ensuring that patients have confidence in the advice provided by pharmacists. The report emphasised the role of community pharmacists in providing patient support which would provide a more effective service through co-operation with local GPs and other NHS facilities.

A further impetus for the development of a lay led, self care strategy within the NHS was provided by the Wanless Report (Department of Health 2002a). In order to meet the demands posed by an aging society on those managing chronic illness associated with greater longevity, Wanless emphasised the need for radical change within the NHS. A key recommendation was the need for a more active “fully engaged” patient, involved in all aspects of health care including prevention, treatment and management of illness and encouraging patients to take more responsibility for their own health (Wright 2002). For Wanless, self-care was identified as a prime example of an effective partnership between the public and the health service. In this partnership, the health service was seen as providing a supportive role, empowering patients to perform self-care activities more effectively. In order to achieve this Wanless called for the creation of a comprehensive self care strategy, including means of financing self care, information and support. Wanless envisaged the successful implementation of a self care strategy would result in fewer visits being made to the GP, a more aware and engaged population and therefore provide an effective and cost effective method of developing an NHS struggling under the weight of demand. The impact of the Wanless report was clear to see. On the day of publication of the final report the chancellor declared real term increases to NHS funding in line with the 'slow uptake' scenario outlined in the Wanless report. The following day *Delivering the NHS Plan: next steps on investment; next steps on reform* (Department of Health 2002b) was published. The report emphasised the "evolutionary" strengthening of patient responsibilities, the introduction of greater choice and the patient as a partner, rather than a simply service user.

The new GMS contract in 2004, laid down a strategy to assist those in general practice to manage their workload. This included the development of minor illness management and self-care education programmes, development of support for Expert Patient initiatives and supporting non-GP based chronic disease management schemes. Further evidence of this shift was seen in the 2004 document *National Standards, Local Action: Health and Social Care Standards and Planning Framework (DH 2004a).* One of the national priority areas within this document was long term conditions, with emphasis on ways to support health by promoting better self-care. In the 2004 *NHS Improvement plan* (DH 2004b) the department of health's commitment to self care again cited with particular attention to chronic illness and also mental illness.

In November of 2004 the Public Health White Paper, Choosing health, Making Health Choices Easier (DH 2004c) emphasised the individuals' responsibilities for looking after ones own health. The paper assured that those who want help to make healthier choices would be supported by NHS health trainers drawn from local communities.

A more detailed description of the self care strategy was laid out in the 2005 document Self care – A real choice, Self care support – a practical option (DH

2005a). The most in depth government paper to date on self care, the publication outlined the reasoning behind the implementation of a self care strategy, highlighting the public's attitudinal change towards looking after their health; what can be done by health care professionals delivering health and social care, and how this can be achieved.

1.3 Self care and decision making

In Wanless' vision of the "fully engaged" patient, strategies to prevent illness and to treat minor illness take place at home or otherwise outside of the health care setting, with the support of primary health care professionals where appropriate. Clearly there is a need to encourage self-care without discouraging appropriate and necessary usage of health services. Presenting self-care and professional health services as having complimentary and mutually supportive roles in meeting common objectives, rather than as two strictly defined alternatives, could help to avoid the patient perceiving the use of one as necessarily requiring or constituting a rejection of the other. Indeed, the main source from which the public currently obtain self care information, and the source which they say they most want this information from in the future, are their GPs. After knowledge and information, guidance from care professionals is regarded by the public as the second most important factor that might better enable them to practice self-care; however they currently feel that professionals are failing to encourage them to do so. (Department Of Health 2005b).

With the re-negotiation of the General Medical Services (GMS) contract for General Practitioners, there came a commitment to identify ways in which the public could be encouraged to take a more proactive role in managing their own health, use services more effectively, or where these services could be offered by other health professionals, especially where these services could be accessed more easily and more cost-effectively than through traditional general practice.

There are thought to be a number of influences on peoples' health decision making. A study of mothers in Canada found that both external influences such as family, workplace and social context, and internal influences such as personal expectations, framed decision making. A study of self care practices in Denmark found that men and women with less supportive social networks were more likely to seek professional help for symptoms.

1.4 The effects of self-care interventions in community settings

Self care support networks or groups are perceived to have positive outcomes including increased understanding and better management of medical conditions, reduced feelings of isolation and increased sense of being understood, empowerment and increased self confidence, feeling more relaxed (Dekker & Lister 2002). Perceived negatives are the possibility that erroneous information may be passed on by peers (Leshem 2003), adverse outcomes may result from unhelpful group dynamics (Dekker & Lister 2002) and providing support could be draining on participants (Colella & King 2004).

Self care interventions have mostly been evaluated in primary care settings.

A systematic review of face-to-face self care support networks with limited professional involvement and aimed at the field of healthcare was carried out in 2006 (Woolacott 2006). Analysis of 46 studies found evidence in favour of peer led weight loss programmes but consistent meaningful benefits were not detected for the majority of studies. There was a lack of evidence from the UK.

Although the public identify increased self-care information as a crucial aspect of boosting their willingness and capacity to self-care (Department Of Health 2005b), Heaney at al’s (2001) RCT study of the impact of distributing self-care booklets to patients of 20 GP practices in Scotland found that disseminating information to patients about the management of minor illness is unlikely to reduce demand for health services by itself. Similar findings came from an evaluation of a cold/flu self-care public education campaign in Canada (Vingilis et al 1998).

There is some evidence that simply providing self-care information may actually increase health service utilization for some conditions (Terry & Pheley 1993), however there are studies suggesting that reductions in health service utilisation for minor illness can be achieved by distributing self-care information booklets (Kemper et al 1993) and other studies suggesting that such booklets do not change GP attendance (van Eijken et al 2004).

McLean & Pietroni’s (1990) evaluation of a self-care programme in general practice suggested that its success was based on promoting a holistic approach to self-care. The study found that patients with high internal locus of control scores (i.e. those who believed that improvements in their health were related more to their own action than primarily to external factors) were less likely to drop out of the programme and more likely to have improved health after a year, whereas those patients who believed significantly more that external factors controlled their health, and that improved health is primarily dependent on luck and chance, were more likely to have remained at a chronic level.

A Danish RCT of a general practice-based intervention involving individual instruction, economic incitement, continuing medical education meetings, feedback/reminder and patient-mediated intervention found a significantly greater decline in number of out of hours contacts by patients in the intervention than control group after 12 months (Christensen et al 2004).

The national evaluation of the Expert Patient Programme (NPCRCD 2006) found that in people with long term conditions, attending a short course on self care skills led to moderate gains in self-efficacy, and small gains in energy, quality of life, psychological wellbeing and partnerships with doctors, although there was no impact on routine health service use (primary care and outpatient visits).

1.5 Issues for implementing self-care interventions in community settings

McLean & Pietroni (1990) argue that the effect of patients' personal beliefs about the control of their health on their willingness to self-care and likelihood of achieving health improvement make an inner directed or internal orientation vital for the successful utilization of self-care and self-help approaches in health. Segall & Goldstein (1989) point out the dangers of allowing self-care to become over-medicalised. There is also a need to avoid self-care practices leading to patients becoming overly focused on ill health (Carr 1990) or feeling a sense of undue blame for their ill health (Segall & Goldstein 1989).

The national evaluation of the Expert Patient Programme (NPCRDC 2006) highlighted a few issues associated with implementation of self care in primary care, including a lack of coherence between the delivery of the course and the actions and advice of professionals working in the health service; individuals' established consulting routines; organisational imperatives to attend for tests etc; difficulty in engaging health professionals (due to desire to be centre of care for people with long term conditions; unfamiliarity or lack of confidence in passing on responsibility to patients); importance of using skilled facilitators to deliver the course; value of social support element of attending the course; positioning of the programme out-with condition-specific long term condition management in primary and secondary care, and unfamiliarity with the term ‘expert patient’; lack of integration with other initiatives and services; limited flexibility (good for inexperienced tutors, bad for adapting to local communities); most effective in PCTs already running community focused initiatives with active and key enthusiast; easy to engage voluntary sector but more difficult to engage primary and secondary providers; and the need for marketing.

References

Anderson, J., Buck, C. Danaher, K. & Fry, J. (1977) Users and non-users of doctors – implications for self-care. J R Coll Gen Prac. 27: 155

Becker G, Gates RJ, Newsom E. (2004) Self care among chronically ill African Americans: culture, health disparities and health insurance status. Am J Pub Health 94 (12): 2066-73

Carr, P. (1990) When over compliance means trouble. Nursing 90: 65-66

Christensen MB, Christensen B, Mortensen JT, Olesen F. (2004) Intervention among frequent attenders of the out-of-hours service: a stratified cluster randomized controlled trial. Scand J Prim Health Care 22 (3): 1880-186

Colella TJ, King KM (2004) Peer support. An under-recognised resource in cardiac recovery. European Journal of cardiovascular nursing; 3: 211-7

Dean, K. (1981) Self-care responses to illness: a selected review. Soc Sci Med 15 (5): 673-87

Dekker F, Lister G (2002) Self-care lessons from Europe: A study from the Department of Health on self-care in the Netherlands, Germany, Denmark and Finland. London: Department of Health.

Department of Health (1999) Saving lives: Our healthier nation. London, DH Publications

Department of Health (2000a) The NHS Plan: a plan for investment, a plan for reform. London, DH Publications

Department of Health (2000b) Pharmacy in the future: implementing the NHS plan. London, DH Publications

Department of Health (2002a) Securing our future health: taking a long term view – The Wanless Report. London, DH Publications

Department of Health (2002b) Delivering the NHS Plan: next steps on investment; next steps on reform. London, DH Publications

Department of Health (2004a) National Standards, Local Action: Health and Social Care Standards and Planning Framework. London, DH Publications

Department of Health (2004b) NHS Improvement plan. London, DH Publications

Department of Health (2004c) Choosing health, Making health choices easier. London, DH Publications

Department Of Health (2005a) Self Care Support: Baseline study of activity and development in self care support in PCT and other provider agencies. London, DH Publications

Department Of Health (2005b) Public Attitudes to Self Care. Baseline Survey. London, DH Publications

Department of Health (2005c) Self care – A real choice, Self care support – a practical option. London, DH Publications

Heaney D, Wyke S, Wilson P, Elton R, Rutledge P, Sommerville A, Wilkie T. (2001) Assessment of impact of information booklets on use of healthcare services: randomised controlled trial. BMJ 322 (7296): 1218

Kemper DW, Lorig K, Mettler M. (1993) The effectiveness of medical self-care interventions: a focus on self-initiated responses to symptoms. Patient Educ Couns. 21 (1-2): 29-39

Leshem RN (2003) Inflammatory bowel disease support groups: a primer for gastroenterology nurses. Gastroenterology Nursing 26: 246-250

McLean J, Pietroni, P. (1990) Self care: who does best? Social Science & Medicine 30(5): 591-6

NPCRDC National Evaluation Team (2006) Final Report: The National Evaluation of the Pilot Phase of the Expert Patient Programme. National Primary Care Research and Development Centre, University of Manchester

Orem, DE, 1995. Nursing: Concepts of practice, 5th. ed. Mosby, Toronto

Paterson BL, Russell C, Thorne S. (2001) Critical analysis of everyday self-care decision making in chronic illness. Journal of Advanced Nursing 35 (3): 335-341

Segall A, Goldstein J. (1989). Exploring the correlates of self-provided health care behavior. Social Science and Medicine 29: 153-161.

Terry PE, Pheley A. (1993) The effect of self-care brochures on use of medical services. J Occup Med. 35 (4): 422-6

Van Eiken M, Wensing M, de Konink M, Vernooy M, Zielhuis G, Lagro T *et al*. (2004) Health education on self-management and seeking health care in older adults: a randomised trial. Patient Education and Counselling 55 (1): 48-54

Vingilis E, Brown U, Koeppen R, Hennen B, Bass M, Peyton K, Downe J, Stewart M. (1998) Evaluation of a cold/flu self-care public education campaign Health Education Research 13 (1): 33-46

Woolacott N, Orton L, Beynon S, Myers L, Forbes C (2006) Systematic review of the clinical effectiveness of self care support networks in health and social care. York: University of York, Centre for Reviews and Dissemination. CRD Report; 34.

Wright K. (2002) NHS funding and reform: the Wanless Report, Research paper 02/30. House of Commons Library.