Background paper 7:

Self-Care: Trends and Policy Implications

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Preamble

This is one of 10 web published background papers which provide detailed analysis and support for the Report: Engaging With Care: A Vision For The Health And Care Workforce Of England, currently with the Nuffield Trust, to be published in September 2007. The report together with the set of background papers provides an analysis of current policies and trends and identifies routes for future action. The report identifies trends and challenges that can help define the common ground in health and care policy, while allowing for different policy directions at national and local levels. The intention is that all those involved in health, in their various roles as paid, informal or self carers, patients and clients, educators, service providers and citizens will be able to understand their roles and contributions and, together with the policy makers, feel empowered to influence health and care policy and practice.

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1 Available at: http://www.jbs.cam.ac.uk/research/health/polfutures/restricted
I. Introduction and Methodology

*Policy Futures for UK Health: Organising and Developing the Workforce* aims to analyse current and proposed policy relevant to care, in order to identify tensions within policy and barriers to the implementation of current and proposed care policy, including self-care and informal care, in both health and social care domains. We have defined workforce to include all those who care, including informal carers and self-carers. The project aims to identify potential solutions and to make recommendations for workforce development and organisation in the future, based on reviews of the extant literature and expert opinion. The programme of work includes an economic appraisal. Our time frame is fifteen years hence.

This paper sets out trends in policy and presents a summary review of the literature on self-care selected to highlight barriers to implementation and to suggest potential solutions to some of these barriers. A summary of themes and their implications for policy are presented in a final conclusion. Very little literature is UK-based; most UK literature relates to the Expert Patients Programme (EPP). The extant international literature does, however, provide insights into how self-care could develop in future.

*Methods*

We reviewed data sources relating to trends in self-care. The aim was to find the most recent data, focusing on trends and projects that have been influential in shaping the present or are expected to impact the future of self-care in England. Data were proactively sought to address these themes. The majority are official data from the Office for National Statistics or part of large-scale national surveys, and available on the web. This was supplemented from alternative, often specialist sources, where necessary.

II. Policy Context

Self-care is a central plank of future English health policy [1-4]. Self-care is supported by a range of other policy initiatives such as National Service Frameworks, the new contract of General Practitioners (GPs) and public health policy [5], and forms an integral part of the new care arrangements emphasising care closer to patients [6]. The Expert Patients Programme (EPP) has been the largest formal self-care intervention in England so far. Other initiatives defined as self-care include NHS Direct and NHS Walk-in-Centres. Alongside new provision of self-care services runs the deregulation of pharmacy, allowing patients greater access to over-the-counter (OTC) medicines and health advice [7].

III. Definitions of Self-Care

The Department of Health defines self-care as “the care taken by individuals towards their own health and well being, and includes the care extended to their children, family, friends and others in neighbourhoods and local communities” [1]. It includes:

“the actions people take for themselves, their children and their families to stay fit and maintain good physical and mental health; meet social and psychological needs; and prevent illnesses or accidents; care for minor ailments and long term conditions; and maintain health and well-being after an acute illness or discharge from hospital” [1].
Wanless defines self-care as that “administered by the individual suffering disease, such as self-medication or self-checks” [8], and this is the understanding most commonly associated with self-care in the literature. “Self-management of chronic illness implies monitoring and managing symptoms, adhering to treatment regimes, keeping a healthy lifestyle, and managing the impact of illness on daily functioning, emotions and social relationships” [9].

Dean [10] suggests that whilst there are numerous definitions of self-care it is essentially about patient autonomy and influence. So, for example, Newman et al (2004) note that the key element of self-management, defined as “taking medication, making lifestyle changes or undertaking preventative action”, is that “the patients, their carers, or both make the day-to-day decisions about what actions are taken” [11].

There is a lack of agreement about where patient autonomy begins and ends. Haug et al [12] argue that self-care can only be performed by the patient without the interference of professionals. Levin and Idler [13] believe that self-care takes place largely outside and independently of the healthcare system. Dean [14] makes a distinction between primary self-care, which includes actions based on the individual's knowledge and experience, and secondary self-care which involves those actions based on information obtained in consultation with laypersons and professionals. For others, the defining feature is that the patient self-manages their illness [15], [16] and this can involve professionals without undermining patient autonomy.

The bulk of self-care literature focuses on formal interventions or processes which are designed to help care professionals support lay people, increase their engagement in healthy behaviour, or to do more disease management.

IV. Policymakers’ Expectations of Self-Care

The Department of Health expects engaging in self-care to improve health outcomes, increase patient satisfaction, and help empower patients to utilise their inherent resources [17].

*Empowering patients*

Greater self-care is seen as a positive opportunity for patients to take control of their illness, that has been increasingly lost to health professionals [10], [18]. Self-care is often defined in terms equivalent to empowering patients. Paterson defines empowerment as “encouraging people to participate as equal partners in the decisions about the health care they receive”. Thus, “health care professionals who adopt empowering practices respect patients’ abilities to make decisions, value their input in such decisions, and are able to relinquish control when a patient rejects their advice”.

*Demand management*

Self-care is seen as a means to help address the growing gap between demand for and supply of care by managing demand for formal healthcare and of containing the costs of healthcare [19]. The Department of Health estimates that 15 per cent of A&E attendances, and 40 per cent of GP time could be avoided, and over two-thirds of GP visits result in prescribing drugs that are available over-the-counter. Whilst this is presented as an added bonus rather than as a driving force behind policy, cost-containment is a recurrent and well-formed argument for self-care policy in England [1, 6], the Wanless review [20] having estimated that for every £100 spent on helping
patients care for themselves, £150 could be saved by the reduction of GP and outpatient visits.

*Improving outcomes*

Self-care is seen as a means to improve outcomes [21]. The evidence of the impact of self-care on improvement of disease outcomes is mixed and inconclusive [22], but there are examples of positive interventions [21], [23], [24]. A recent *Rapid review of the current state of knowledge regarding lay-led self-management of chronic illness* [22] concludes that lay-led self-management programmes “have the potential to enhance the participant’s abilities to cope with illness”.

V. **Who Self-Cares?**

A plethora of variables associated with the person predict self-caring. Being younger, [25-27], white [28], [19], more educated [25, 26], of higher economic status [9, 29], employment status [19], and more affluent [18], [21], [28] predict levels of self-care.

Illness itself and the reaction to illness are also important predictors of self-care. Significant variables include the stage of illness [25], the severity of condition [9, 25], the kind of illness, [26], any co-morbidity [30], and adverse effects of medications [30]. Jerant et al’s [21] Californian study found joint pain, immobility, fatigue and depression to constrain people’s ability to self-care.

Those who suffer disproportionately more ill health [31], [32] are also those who are difficult to engage in self-care initiatives [17, 33] – these are the elderly, the deprived and ethnic minorities.

Negative attitudes to healthcare providers [54] and treatments [25] can also promote self-care activity. Sowell et al. [71], for example, found HIV positive patients in the USA switched to self-care when they did not trust their health care provider or treatment.

VI. **Barriers to Self-Care**

*Patients:*

It is not yet clear that there is public demand for self-care [34]. Patient willingness to self-care depends partly on how self-care is defined. Asked if they perform particular activities, the general public report high levels of engagement in self-care [35]. In 2005, the DH presented research that showed that “nine out of ten” in the public are interested in administering self-care (in the survey characterised as “lifestyle and taking care of minor ailments, long-term conditions and following discharge from hospital”) but that lack of information, time and money are the main barriers to self-care [36]. Some also fear that self-caring will exclude them from formal health and social care. [37]. The DH believes that “self-care does not necessarily take more time and money”, and the “public may need to be better supported to increase motivation before behaviour is likely to change”. The report concludes that “there do seem to be some issues around levels of active interest and motivation”. More than half of the public surveyed said they were rarely advised to perform self-care, and a third said they had never been encouraged to do so [17].

The current literature does not support the assumption that patients seek to be empowered and to self-care. Patients do not necessarily seek control [18], [38], [39],...
and being ill reduces its importance further [40]. There are times where “being cared for” was valued over being empowered [40], [28]. For example, O’Cathain et al.’s study [41] of NHS Direct, found that patients used NHS Direct as a means of accessing or expediting formal care and to legitimate their demands for formal care. O’Cathain et al. [41] found that some users of NHS Direct were frightened by the responsibility they were given to make choices, and felt forced into being active. Others found it difficult to be assertive when they or someone else was ill. Others see the job of providing care as that of the doctor. For example, Greenhalgh shows how the idea of self-care is anathema to British Bangladeshi who see lack of symptoms as being well and therefore do not see a need to practise preventative self-care, but, moreover, see maintaining wellness as the job of their doctors [42].

Patients may choose to engage in unhealthy behaviours in order to be empowered. Gough and O’Conner use the idea of reactance [43] to explain why men deliberately choose not to follow healthy eating habits. Fogarty uses the same concept to account for patient non-compliance [44, 45]. In both cases, individuals are not compliant because they place greater value on their freedom to choose and independence and object to being told what to do.

Indeed, the idea of several conflicting goals is often used also to explain why some patients face difficulties in self-caring given their social context [46], [28]. Schreurs et al. (2003) note how patients have several goals which can easily be conflicting. If self-caring behaviour requires an individual to change their social networks or social practices which reduce quality of life, it can seem deeply unappealing [47], if not impossible to achieve [21, 28]. Some patient groups lack competence to self-care [38].

In other cases patients may not see health messages as relevant to them. For example, Greenhalgh et al [48] report how British Bangladeshis may struggle to engage with official health messages when they do not have a word for “physical exercise” and attribute high levels of diabetes to a lack of sweating.

| Health and care Professionals:|

Professionals’ attitudes to patients who self-care is often ambivalent [49]. One evaluation of the Expert Patients Programme found that “The positive engagement of health professionals and GPs in particular has been slow to emerge” [33]. Furthermore, “[p]romoting engagement was viewed as an onerous and time consuming activity by Primary Care Trust leads. Professionals were viewed as non-receptive to the idea of user-led initiatives…” [33]. The Department of Health itself concedes that: “awareness of the scope and potential for self-care among care professionals was perceived to be, at best, patchy” [17]. Thorne et al. [50] suggest that professionals doubt patients’ ability to make decisions for themselves and use “blocking tactics” [51], castigation, anger, and superior technical knowledge to bamboozle patients [52]. Professionals who do see patients as “partners” tend to view patient participation as gaining active agreement to comply with treatment regimes [53]. Thorne et al. [50] call this the “paradox of self-reliance and compliance” [54]. On the one hand, patients who self-care are seen as being in control of their own illness; at the same time they are expected to comply with the advice of professionals. “The power to label a patient noncompliant rests with the professional” [55] [54] who remains the ultimate expert. Fox et al. [56] note how this imbalance in power is reflected in the language of patient participation; patients are “involved” [57], “autonomous” [58] and “resourceful” [59].

Self-care privileges some behaviour over others and allows doctors to extend the medical gaze into areas hitherto held to be private [15]. Sachs [47] and Førde [60]
see health promotion activities as a moral project that subjugates individuals and assigns guilt. Kickbusch [61] talks of self-care’s “middle class bias”. Miewald [28] argues that “chronic disease requires that patients internalise the doctor’s role and care for themselves”. Sachs [47] argues that this issue of subjugation and blame is particularly germane when patients change their behaviour which is then not reflected in clinical or symptomatic measures [11].

Discussion at a recent seminar at the British Medical Association (BMA) revealed that many GPs are ignorant of the EPP, not least because it is difficult to get access to course details and materials. General Practitioners expressed concern that they were unable to refer patients to programmes such as the EPP and self-management programmes with confidence because of the lack of data of what is appropriate for which patients [62]. Primary Care Trusts, responsible for commissioning self-care, have expressed similar fears: “The main perceived risk to the public was delayed consultation and resulting adverse effects on health [17, 36]. Some patients sharing this view [37] may increase professionals’ reluctance to encourage self-care.

The Healthcare System:
Embedded in the many concepts of self-care, and the fully-engaged patient, is the idea of enhanced relationship between patient and practitioners. Patients use the knowledge of professionals to support their decision-making. Patients who self-care are still required to fit in with the “institutional constraints” including “time schedules and dwindling resources” [18]. Jerant, et al’s [21] Californian study highlighted barriers to self-care associated with service provision (being rushed by doctors, waiting for test results, waiting for referrals). Paterson [53] suggests that if patients are rushed to make a decision they are likely to allow the professional to make it for them; and Coulter suggests that if practitioners are hurried they will default to prescribing [25].

Moreover, self-care typically relies on individuals accessing and using information from health professionals and other sources. This may favour some patients over others [63]. Morgan [64] notes how younger, more educated, and more middle-class patients seek more information from doctors (see [65], [66]) and doctors tailor their information provision to the perceived needs of patients [67]. This can result in a “double-jeopardy” of passive patients receiving less information because professionals perceive them to be indifferent or incapable.

Self-care often relies on individuals accessing and using information. Patients need to be able to read and to understand and speak the language in which the literature is produced [29]. Information needs to be appropriate [29, 68]. Coulter’s [69] analysis of material produced for the Expert Patient Programme concluded that “far too many adopt the paternalistic view that patients cannot cope with bad news and must be kept ignorant of medical uncertainties. Patients are seen as ignorant children in need of instruction and reassurance, rather than as experts in their own needs and preferences. Benefits of interventions are emphasised, risks and side effects glossed over, and scientific controversies hardly ever mentioned. In too many cases the information contained in patient information leaflets is inaccurate or misleading.”

There are also physical barriers to self-care. Focusing on the experience of older people in residential care in Sweden, Sacco-Paterson and Borel [70] find that older people in residential homes face special physical and cognitive barriers to self-caring. In their study, for example, residents with highest functioning were placed furthest from the toilet, thus placing them too far away to remain independent, as residents with most dependency were placed closest to nurses. Whether a resident was “diapered” or given a commode depended on the physical space around a bed.
Mixed toilets and bathrooms made the female less comfortable with using them and discouraged residents from maintaining their independence. Residents did not communicate their discomfort or distress because they thought the staff would already know. Age-related cognitive impairment made it difficult for those residents experiencing memory or reasoning problems to learn and embed new routines. Culturally and psychologically, residents “accept the situation”, thus eroding their inclination and ability to self-care over time.

Jerant, et al [21] highlighted practical barriers to accessing self-management services including lack of awareness, immobility, transport problems and cost. Many participants in this Californian study expressed an interest in home-delivered support services.

VII. Evidence of Self-Care Meeting Policy Expectations

Empowering patients

Many argue that due to systems constraints and professional attitudes and practices, patients are not enabled to take control [50], [52]. Furthermore, some argue that the self-care policy is not to empower, but to shift blame and responsibility onto the individual [15] and [39]. It follows that self-care allows professionals to pass responsibility for getting well to the patient [73, 74] [75] and to “blame” the patient [76]. This is seen as particularly expedient where a professional cannot cure or meet other patient expectations. This does not give patients autonomy, but adds the weight of responsibility for getting well to their concerns [39, 77].

Demand management
The impact of self-care on demand for formal care services is as yet, unproven, but evidence can be found to support that view [78], [79], [80]. For example, McWilliam et al. [46] designed an intervention for older people (aged over 65) discharged from hospital with a chronic medical condition. Controlling for gender, living arrangements, range of medical conditions, and baseline scores, differences in healthcare utilisation were not significantly different between the control and intervention groups.

How self-care is defined is linked to what it is expected to achieve, which in turn has implications for service provision. For example, in the English context self-care policy includes NHS Direct, a phone service staffed by nurses for patients, yet these are services provided to patients on demand by professionals (nurses). NHS Direct may reduce demand for face-to-face contact with GPs (although even this is not proven), but not demand for more formal care per se. Perhaps the difference is that the service provides advice rather that treatment. However, the expectation that higher levels of self-care will reduce demand for formal care is contested [81]. Indeed, many anticipate increased demands on professionals' time [26], [82]. PCTs fear, at least in the short term, the “increased demand for resources” with the implementation of self-care [17]. Patients, after all, will need professional guidance in order to self-care and become expert patients [25]. Clinicians will need to spend more time explaining and negotiating with patients and this will require more staff and new training in how to interact with patients [25]. Many self-care programmes deemed to be successful from other countries show that costs are incurred through
the additional time professionals spend with patients, and the specialist training required to make programme facilitators effective [11].

Furthermore, demand management rests on the belief that better understanding of when to access, and better understanding of when and how to self-care, will reduce inappropriate utilisation of healthcare services. Thus a distinction is drawn between “appropriate” and “inappropriate” demand [83]. Where to draw the line between the two is contested. Mohler and Harris [83] argue that not seeking help when a medical intervention could improve health is also inappropriate. Whilst current policy stresses the importance of inappropriate over-use of formal care services, there are also concerns about equitable access [84]. Some argue that demand management will reduce access to care and result in poorer outcomes (eg [85], [86].

Improving outcomes

The health outcomes of self-caring for long-term diseases are not known at present. Heneghan et al. [72] report that self-monitoring and adjustment of oral anticoagulation has a positive effect on outcomes, but is not suitable for all patients. Self-monitoring is associated with higher frequency of testing, and therefore more responsive care and better outcomes. Newman et al compare efficacy of self-care interventions for diabetes, arthritis, and asthma and give some insight into what makes a programme more successful and or cost-effective, yet they caution that current data do not give a coherent picture. For example, they note that across the studies under review no difference in patient outcome was observed depending on whether a course was lay-led or professional-led. However, the former are cheaper and the latter better for dealing with factual information. There are, however, a number of studies which show changes on some measures, but not necessarily health outcomes [11, 87], and a number of studies which conclude that greater levels of self-care do not harm [88], [89].

There is room for optimism, nonetheless. In a recent UK study, Brown et al. [90] did an RCT in London with 140 men who were split into two groups, with one receiving standard care for uncomplicated urinary tract symptoms, and the other taking part in three sessions including lifestyle advice, education about their condition, and goal setting. Three months later, 42% of the group receiving standard medical help experienced a treatment failure, which meant that their symptoms increased, or they needed drugs or surgery. This was true of only 10% of the self-managing group. These differences increased through the year-long study.

VIII. Necessary Ingredients for Supporting Self-Care

Given the broad range of activities, supported or otherwise, that are considered to be “self-care”, drawing together lessons for future success is difficult. However, current literature gives clues of what should at least be considered and how these may help policymakers anticipate future needs.

Explicit Purpose

In order to achieve desired outcomes, it will be important to prioritise patient empowerment or demand management and to reflect these objectives in programme design. For example, Newman et al’s [11] review of self-care interventions for asthma, diabetes and arthritis show mixed evidence of self-care reducing demand for services. This they explain partly by differences in the focus of the course.
An asthma course aims specifically at reducing emergency care, in a way that the other two diseases do not need to. Newman et al [11] argue a need to ensure that programmes are appropriately disease specific or generic.

Changing Patients or Professionals?
Van Dam et al [87] review the effect of patient-provider interactions of diabetes self-care. Studies cited find that training GPs to engage more with patients did not improve self-care, but did improve satisfaction [91]. Patient interactions with nurses in the same study improved patient perceptions of care, but not patient perceptions of improved capacity to self-care [92]. By contrast an automated telephone system giving test results did improve efficacy, satisfaction and quality of life ratings [93], [94]. Anderson et al’s study [95] of a patient empowerment education programme yielded similar results on self-care behaviour and patient satisfaction. From a review of eight studies, van Dam and colleagues conclude that interventions that focus on patients are more successful than provider-focused interventions (eg automated telephone management programme, the patient group, group consultations [96]. One reason offered for the disappointing results associated with provider focused interventions is that providers equate, wrongly, their giving patients more opportunity to participate in consultations with patient empowerment.

Developing Self-Efficacy and Individual Capability
Current policy assumes that engaging in self-care will increase self-efficacy [97]. Self-efficacy describes the “confidence in one’s power to perform required behaviour and influence the progression of the disease” [87]. Self-efficacy is associated with greater self-care tendencies [98], [9], [21] and may lead to self-care rather than result from self-care. Many self-care programmes developed in North America appear to make self-efficacy their central aim. They do this because “Higher levels of self-efficacy are associated with more optimal self-care behaviours, and interventions can strengthen patient self-efficacy and result in positive changes in health behaviours and improved health outcomes” [21]. The stronger a patient’s self-efficacy beliefs, the more control they feel they have over their disease and over their ability to prevent complications by improving self-management behaviours [9]. Thus empowerment and improvement are linked. Self-efficacy is predicted on previous experience, vicarious experience, verbal presentation, and other psychological factors such as distress, and can be developed through teaching patients problem solving and goal setting skills [11], for example, but it should not be assumed that giving patients the “right” to self-care will develop their self-efficacy or their desire to self-care.

For self-management to be successful it needs to include the “ability to monitor one’s condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life” [99] cited in [11]. This goes beyond providing information – which typically increases knowledge but does not result in behavioural change.

There are a number of potential approaches to improving patients’ ability to self-care, other than through formal attempts to increase self-efficacy. Schreurs, et al, [9] designed an intervention that attempted to develop self-regulation – “the process by which people control and direct their own actions in the service of meeting their goals” by developing proactive coping skills and action planning. The intervention involved five 2-hour group sessions facilitated by nurses, and patients were expected to do homework. Schreurs et al suggest that those who dropped out of the course were most likely to be in denial about having a chronic illness. Strengths of the programme were the opportunities for goal-setting with support. Participants learned how to set goals that were self-generated, positively formulated and achievable [100].
“Relevance, individualisation, feedback, reinforcement, and facilitation have been shown to increase the effectiveness of interventions” [9].

McWilliam et al. [46] designed an intervention for older people (aged over 65) discharged from hospital with a chronic medical condition, based on the adult education theory of “perceptive transformation” [104], aimed at improving patient self-care, as well as a positive attitude towards life. The intervention started with a “reflective dialog” about how life would and needed to be different in future, and was followed by 12-16 home visits. The analysis controlled for gender, living arrangements, range of medical conditions, and baseline scores. The intervention group expressed greater ability to manage their own health, had lower information needs, and showed more significant declines in self-care agency and locus of authority overtime (one year later), compared with the control group. Quality of life was higher for the intervention group.

Newman et al also comment that whilst theory is implicit in many of the self-management programmes they reviewed, it would be helpful in developing programmes in the future to have the theoretical underpinnings made more explicit in order to evaluate which approaches, or aspects of approach, are most valuable to patients. It would also be helpful to design programmes to develop specific skills and not assume they will develop incidentally.

**Appropriate Staffing of Programmes**

Wormald et al. [105] evaluated an intervention targeted at increasing levels of physical exercise in deprived communities in Hull. Based on interviews with programme participants Wormald et al. set out a number of factors for success – including adequate and appropriate (empathetic and approachable) staff and ongoing support, and other services such as dieticians, as well as accessible information. The success (that is, client satisfaction) depended on patients having a lot of contact with professionals over extended periods of time.

Bhalotra and Shepard [106] conclude from their US study that a successful behaviour modification programme requires “champions within the institution providing services, interest by referring clinicians, data systems for tracking patients across institutions, and support systems for encouragement, relieving anxiety and, when needed, arranging transport”. (See also Blamey et al's evaluation of Have a Heart Paisley [107], [108]).

**Appropriate Training**

Appropriate training for facilitators is also essential for ensuring the success of a programme. Newman et al conclude that course leaders, be they health professionals or lay tutors, need to be trained in specialist approaches appropriately (eg in cognitive behavioural therapy (CBT)). This has implications for the cost of programmes.

Professionals need to keep abreast of services and facilities in order to refer and advise patients accordingly [105].

Heneghan et al. [72] argue that self-monitoring of anticoagulation is not suitable for all patients, not least because patients must be prepared to take part in (and capable of learning from) the extensive training required.

**Variety of Provision**

Differentiated provision appears to be a strength. Schreurs et al's [9] evaluation of a programme designed to increase self-regulation, found that older patients gave more
positive evaluations of the course, and those who were working and those who were more educated gave lower ratings. The structured approach did not suit everyone. Newman et al’s review of a number of interventions suggested that lay-led programmes have some advantages and disadvantages, the same as professionally-led programmes. One example in their review of an intervention using the internet did not yield positive outcomes, yet some sort of remote approach seems attractive to overcome mobility and transport difficulties, and van Dam et al [109] cite a study which used internet-based peer support with success.

The answer may lie in providing different services to different people. For example, van Dam and colleagues [109] explore the effect of different modes of “social support” for diabetes patients. Their review of six randomised control trials found that social support received from spouses, family and friends had no effect on outcomes, including self-care and life-style modification [110], [111], [112]. By contrast, studies showed some positive effect for group consultations, internet or phone-based peer support and social support group. Van Dam et al. [109] also observed differences in effects for men and women and suggest that support programmes should therefore vary in approach.

Improving Access
Many programmes, including the EPP [33] find recruiting patients difficult. Bhalotra and Shepard [106] describe a successful US self-care intervention used to support “life-style modification” designed to reduce the risk of congestive heart failure (CHF). They evaluate two programmes aimed at changing diet, physical exercise and management of stress, which require patient participation in support groups. Recruiting patients was difficult. Different participants were recruited by different means, and how they were recruited had implications for retention. Bhalotra and Shepard suggest that one solution to improved recruitment is to engage in active social marketing targeted at specific groups. Many participants were recruited through networks, suggesting that programmes must be embedded in communities.

Within this US context an issue relevant to participation was funding, with patients expected to co-pay, and providers were reluctant to provide programmes which are costly. Costs of self-care are currently an issue for patients [113], yet the EPP is currently free to patients. The EPP has recently been established as a community interest company (CIC). The implications of this are as yet unknown. However, there is considerable evidence to suggest that payment schedules influence access to formal care [106] which needs to be taken into account when designing accessible and equitable services.

Improving Physical Access
Both physical design and geographical proximity are relevant to access. Sacco-Paterson and Borell [70] argue that greater consideration must be given to the physical and socio-cultural environment in which care takes place if people are expected to self-care and be independent.

In Wormald et al’s [105] evaluation, an intervention targeted at increasing levels of physical exercise in deprived communities in Hull, set out a number of factors for success: feasible access to facilities and linkages with other services such as dieticians. Transport was noted as a barrier to self-care in the Department of Health’s survey of public attitudes [37].

Jerant et al [21] conclude that future self-care services should aim to develop self-efficacy and also enable it. That is, objective barriers to services, such as mobility issues and transport, cannot be overcome through psychological interventions. More
provision of home-based services would address many of the access problems by reducing the cost to individuals who are ill.

Engaging “hard to reach” groups may require more proactive approaches and more decentralised provision.

**Appropriate Technology**

Supporting self-care in the future will depend on developing appropriate technologies and support processes. For example, Heneghan et al. [72], whilst showing that self-monitoring of anticoagulation therapy gives patients independence and improves outcomes, note that success is contingent on developments in technology: One problem...“is the high cost of test strips. The reliability of self-monitoring devices can affect test results; however available devices give INR results that are similar to those obtained by laboratory testing”.

Other technologies include the availability of appropriate alternative sources of advice and support [83].

**Developing Guidelines**

This is likely to be an important feature of future policy, but as yet lack of coherent data and comparable evidence prevents GPs and commissioners from knowing how and why to expect patients to self-manage.

Heneghan et al. [72] note the importance to ensuring patient safety of having, and following, guidelines in self-managing anticoagulation therapies.

**IX. Summary of Themes and Implications for Policy**

- Current policy seeks to blend three major aims: health improvement, better resource management, and patient empowerment. Policy is thus attempting to pursue three objectives which are not readily aligned.

- Policymakers appear to be ahead of the public and patients in demands for self-care. Under the current arrangement it seems unlikely that expanding self-care can be left to itself, as there is no clear evidence that patients choose to self-care. Many studies note the difficulty in recruiting patients to self-care programmes, and not all individuals have the capacity to self-care [114], especially those who are ill.

- There is no clear data that self-care activities improve outcomes or reduce demand for formal services or save money. The significance of this will depend on the importance of these goals relative to the value given to patient choice and empowerment.

- Evaluating the effects of self-care on health outcomes and service utilisation is not helped by the lack of clarity around what self-care is or should be. Different definitions of self-care mean that different initiatives are included in different studies, which makes drawing general conclusions more difficult. This inability to generalise from current studies is made more difficult still by previous interventions having clustered around particular diseases (especially diabetes) [19] and around certain population groups, and around different outcome measures [87]. There is significant variation in approach and underlying assumptions: some programmes focus on psychological models, others on information; some are disease specific, others general; some are...
very specific and others far-reaching - INR testing versus complete overhaul of life-style.

- Many of the studies are from the USA, leading to questions about how useful evidence from the USA will be to predicting outcomes in the UK healthcare context. Moreover, self-care activities have to be understood within individual social contexts. Greenhalgh [42], for example, suggests ways in which the health beliefs of British Bangladeshi diabetics can be used to build self-care advice where there is some convergence with official health messages.

- Evaluating the broad range of practices currently called self-care initiatives within a common framework or taxonomy would provide information on which to judge what is the most appropriate for individual patients in future. A better understanding of what self-care is and can do for which patients would allow self-care options to be integrated into a broader framework of individualised care.

- There are potential lessons to be learned from existing studies of interventions:
  
  - The expansion of self-care in the future will require that patients are given more than simply access to information and more “say” in a consultation. They will need to be empowered in the sense of having “power within”, and sense of being able to self-care.
  - Interventions which aim to increase patient self-efficacy and active coping skills show particular promise.
  - The physical and social environment in which the patient lives is also important. For some patients facing difficulties in mobility or transport, self-care support delivered in their home is one option to be considered. Alternative sources of social support may also prove useful.
  - Networks appear to be important for recruitment to programmes and retention. GPs in particular, but other formal care workers, can be a conduit to self-care programmes.
  - Interventions aimed at changing patients appear to be more successful in promoting behaviour change than those that aim at changing practitioner behaviour. However, practitioner behaviour is clearly relevant in providing support for patients to self-care.
  - The type of support offered to encourage self-care activities appears to be influenced by the patient type, suggesting a need for a range of approaches.
  - With some patients a continuing relationship with a care professional is central to their continued adherence [105].
  - Many programmes rely on professional staff trained in particular skills, for example, nurses trained in CBT.

- Gaps in current policy relating to cost-containment include answers to questions of what happens to those people who will not or cannot self-care, and whether this difference matters to entitlement; whether there is a substantive difference between those who self-care to protect their health and those who self-care with the onset of illness; and what happens if the burden for care is passed to other carers such as informal carers.
Another major concern is the potential that policymakers’ expectations for patients to self-care will exacerbate inequalities in the future, particularly if self-caring demands greater personal income or other resources that influence individual choice. Current research suggests that some patients are better placed than others to engage in a more equal relationship with practitioners, and that it is those with the least need for care who are more inclined to care. In the future, if an individual lacks resources but is expected to self-care, this will result in a downward spiral of disempowerment.

X. Themes for Further Development

Policymakers expect more people to self-care in the future. This paper presents a number of definitions of policy and extracts a summary of policy expectations. It identifies the key barriers to implementation, relating to patients, professionals and barriers within the care system. The paper presents evidence of self-care meeting policy expectations (or not) and draws attention to tentative recommendations for developing effective self-care policy and practice in the future.
XI. References


64. Morgan, M., Hospitals and Patient Care, in Sociology as applied to medicine, G. Scambler, Editor. 2003, Saunders: Edinburgh. p. 66-77.


