Long term conditions: from dependency to responsibility

This document reports on the efficacy of the current models of care for people living with long term conditions, and will investigate the possibility that new services and new technologies can help re-design the way care is delivered for long term conditions.

It defines a new model of segmentation for people living with long term conditions that is complimentary but additional to the traditional Kaiser Triangle – and shows how this model can help us define packages and systems of care that are appropriate and personalised to patient needs.

What is a long term condition?

Long-term conditions are those that can only be controlled and not, at present, cured. They included diabetes, asthma, chronic heart disease (CHD), chronic obstructive pulmonary disease (COPD), sickle cell anaemia, dementia and a range of disabling neurological conditions. They usually require careful monitoring and management, including through self-care[1].

Current prevalence and care model

Approximately 17.5 million people are living with a long term condition, and some, especially older people, are living with two or more long term conditions[2]. Thus far, care for people with long term conditions has been reactive rather than proactive, typically unplanned, and subject to geographical variations in quality and service model[3,4]. This sporadic model of care has caused patients' conditions to become out of control, their health to deteriorate, and finally to unplanned, resource intensive and distressing acute interventions[5]. This is especially true for our most vulnerable citizens, who often feel unable to cope with and manage their condition(s).

Deprivation, lifestyle and rising prevalence

Almost all long term conditions are strongly statistically correlated with deprivation, specific ethnic groups and social disadvantage[6,7]. There are many reasons for this correlation including: a lack of education; poor access to information and health services; poor diet and nutrition; a lack of exercise; a high prevalence of substance and alcohol abuse; and a high rate of obesity and smoking[8].

The prevalence of the most common long term conditions is also increasing, due to an ageing population, an almost epidemic increase in obesity, and the lack of healthy diet and exercise especially amongst the poorest in society. For example, the prevalence of type 2 diabetes is set to double over the next 25 years[9] and at this very moment there may be up to 1 million undiagnosed type 2 diabetics receiving no treatment whatsoever for their condition[10].

Historical trends – from healthcare to self-care

Historically the NHS has been focused on delivering excellent quality care, free at the point of delivery, based on clinical need and not ability to pay. However, this focus on delivering care can imply a neglect of maintaining health, or promoting self-care and self-reliance. Given the rising prevalence of long term conditions, and the fact that the conditions themselves and acute escalations can often be delayed or prevented, it has now become imperative for the NHS to move on to become a true health service and not just a sickness service[11].

Economic case for health promotion and self-care

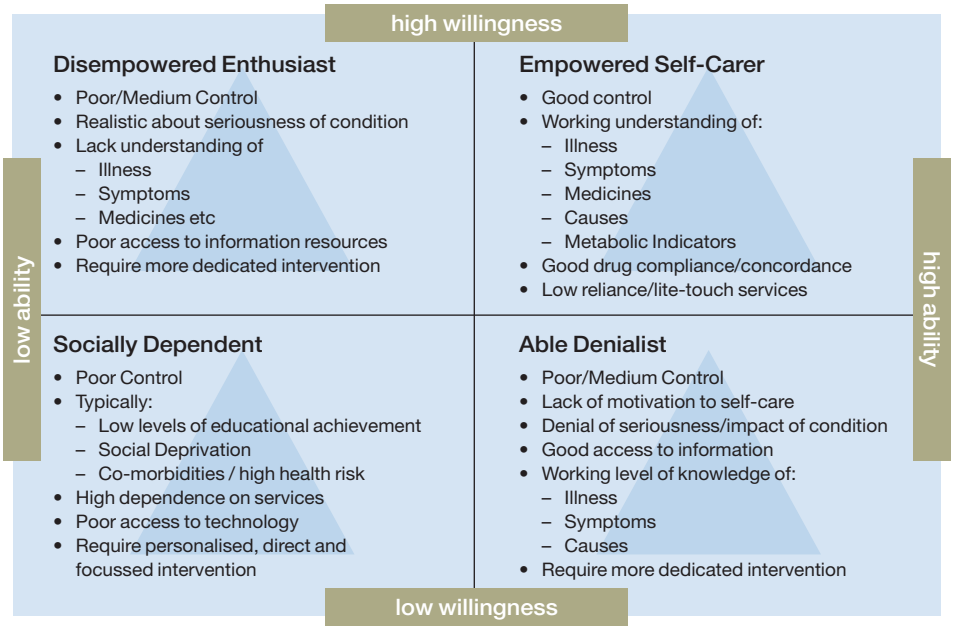
This new philosophy of promoting health, self-care and self-reliance makes economic as well as clinical sense[12]. Even with the historic programme of investment in the NHS within the last 8 years, the service is still often running at full capacity, and may not be able to cope with large percentage increases in acute escalations from long term conditions. Furthermore, economic inactivity is often associated with ill health, reducing available resources through taxation needed to fund the NHS. If we are to create the means for each citizen to realise their true potential – and a community in which power, wealth and opportunity are in the hands of the many, not the few – then it is imperative that we empower the most vulnerable and the most deprived people in our society with the means to make informed choices to maintain their own health, and to manage their conditions should they arise.

The importance of a patient-centric approach

Yet currently, despite the necessity for a patient-centred approach that empowers people to take responsibility for the care of their own condition, the prevalent models of patient segmentation are based on risk of escalation, not on patient behaviour, attitude or aptitude. In order to move from a state of dependence to one in which the rights we enjoy reflect the responsibilities we owe, it is critical that we understand the ways in which we can encourage people, through their own actions, to take more responsibility for the treatment and management of their own conditions. This requires a personal model based on the patient, as well as the severity and risk associated with the condition.

A model to recognise the complexity and behaviour of the patient

A new model of stratification and treatment is therefore required in the NHS for people with long term conditions. This model should clearly define the sorts of services that are appropriate to deliver to each type of patient, building on the risk structure provided by the traditional Kaiser triangle. The 4-box diagram below defines this new model:



It is important to recognise the role of the community, and community based research programmes, in the stratification and assessment of patient groups

Clearly each of these groups requires a different intervention type. For example, interventions that might be appropriate for the empowered self-carer would assume too high a level of knowledge and ability for the socially dependent, whereas interventions for the socially dependent would be too intensive and resource-consuming for the self-carers. Furthermore, the goal of any intervention for patients not in the empowered self-carer quadrant should be to migrate, if possible, that patient into that quadrant. Mobility through these quadrants, like social mobility, is dependent on the power of education and knowledge and the spark of understanding and motivation, and therefore services should be designed to encourage this mobility.

This model compliments the Kaiser triangle by suggesting the shape and type of services for each type of patient, and by recognising that patient behaviour and response to services is driven by their will and ability to act, rather than necessarily by their risk of escalation. By segmenting patients in this way we can choose services that will have the highest probability of positive response given the patients' level of knowledge, their general ability, and how willing they are to manage their condition and take it seriously. The model is also generalisable outside of the immediate sphere of long term conditions management, to related areas such as general health promotion, weight management and smoking cessation.

Finally, it is important to recognise the role of the community, and community based research programmes, in the stratification and assessment of patient groups[13]. Whereas the primary responsibility for stratification and assessment on an individual patient basis lies at the GP level, the targeting of wider programmes and initiatives aimed at communities will require sensitivity and understanding of the habits, lifestyles, beliefs and customs of people living within those communities. Good research is therefore critical, but more than this, the willingness to work with partners such as the Post Office, supermarkets, pharmacies and all other stakeholders that make up the fabric of a community will enable health services to provide more effective outreach, and better population level interventions.

New services built around the patient

Once patients have been stratified and categorised by their GP or primary care-giver, it is necessary then to design and build services that are appropriate to each patient group. However, the variety of possible services can be confusing. Furthermore, outside of the 5% of patients who require case management, a question remains concerning the economic viability of managing such a high volume of patients. Here we evaluate different types of services, and how they relate to the patient groupings in the 4 box model above.

Case management

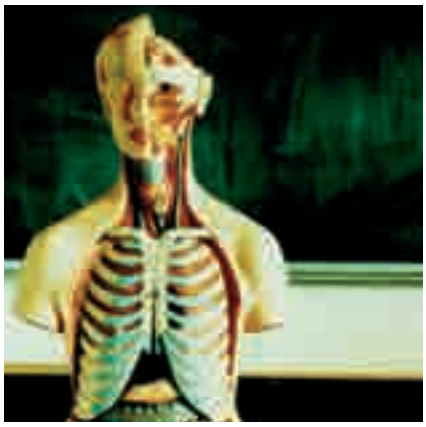
Case management essentially consists of using a clinician, (usually a community matron), to anticipate, manage and join-up care across health and social services for high risk patients - typically older people living with 2 or more long term conditions, taking 4 or more prescription medications, requiring frequent acute intervention, and making up approximately 5% of the total number of long term conditions patients. LTC Patients within the Socially Dependent quadrant are more likely to require Case Management services because they are less likely to adopt an effective self-care programme without such high intensity intervention due to the complexity of their condition. Furthermore, since Community Matrons will typically be working with older people it is vital that co-morbidities, and especially mental health co-morbidities such as dementia, are taken into account – and that Case Management services are effectively integrated with assertive community outreach programmes in Mental Health Trusts.

There are several different methodologies of case management. However, the Kings Fund review of competing case management methodologies found that no methodology was significantly superior to any other[14], although some positive results have been reviewed. For example, the Castlefields model found a significant reduction in length of stay, total bed days and admissions, saving a significant amount of acute capacity.

Remote patient monitoring

Remote patient monitoring comes in several forms. At its most technologically advanced it can involve elderly or vulnerable patients being constantly monitored by sensors in their homes, or indeed metabolic sensors carried around with the patient. Less invasive monitoring is possible with the periodic use of electronic metabolic measurement devices that upload metrics to a central database, producing automatic alerts at pre-set levels for carers or clinicians. Such approaches have proven very successful indeed at preventing escalations and providing better patient care[15,16]. However with all forms of remote patient monitoring, but especially the more technologically complex and invasive forms, it is important to put in place a robust system of patient concordance and consent to preempt any medico-legal and ethical issues.

Remote patient monitoring is inappropriate and unnecessarily complex and expensive in the treatment of empowered self-carers, but has very positive results for disempowered enthusiasts and able denialists who have poorer control and require education and motivation respectively. The technology can be used both to improve concordance and educate a patient, as well as providing clinicians with up-to-date information to prevent escalations before they happen.



Studies have shown that educating and following up patients can slow or reverse the deterioration of their condition, as well as increasing confidence and control

Proactive contact centre management

Proactive contact centre approaches to the management of long term conditions solve the problem of high cost, face to face interventions by employing tele-carers and facilitating a much higher case load than a district nurse or community matron could possibly take on. The proactive contact centre approach has been shown to work on its own[17,18] or more effectively in tandem with remote patient monitoring[19]. Research also shows that the approach is acceptable to patients[20].

Proactive contact centre management is of limited effectiveness for patients with good control however, but can be very useful in motivating and educating patients. The approach also bridges the digital divide for the socially dependent, given that over 99% of homes have a telephone and most people are happy with their use. Therefore this approach is suitable for disempowered enthusiasts, able denialists, and some socially dependent patients.

Patient education programmes, support groups and advocacy

Whereas contact centre management approaches, especially in conjunction with remote monitoring devices, do provide a certain level of education and awareness to the patient – it is often necessary and appropriate to provide dedicated, face to face education for patients. This can be very effective – and studies have shown that educating and following up patients can slow or reverse the deterioration of their condition, as well as increasing confidence and control[21]. Studies also show that the efficacy of patient education can be augmented when used in conjunction with remote patient monitoring technology[22].

Patient education and support groups are especially appropriate for the disempowered enthusiast who lacks the practical or theoretical skills to self-manage their condition, and also for able denialists where motivation and understanding is required in order to start managing the condition and complying with treatment. This approach is also effective with a proportion of the socially dependent, where self-management of the condition is a practicable future goal. Whereas the intervention itself may be unnecessary with empowered self-carers, expert patients can be a powerful tool in the community to run patient education and outreach programmes, especially to ethnic minority communities, if properly trained and managed[23].

Furthermore, in communities where language and culture can be a barrier to care, it is particularly important to put in place strong patient advocacy and translation services to compliment support groups and education programmes, to make these new and existing services accessible and welcoming to diverse groups of citizens.

Concordance/reminder systems

There are approximately 9 million Did Not Attends (DNAs) per year in the NHS, costing £300M[24]. Furthermore, only 50% of drugs are taken as prescribed[25]. This endangers the patient, encourages the evolution of resistant bacteria, and costs money. Systems that remind patients to take their medicines appropriately, or to attend scheduled outpatient appointments, are therefore necessary as part of a framework of services in the treatment and management of long term conditions.

Concordance and reminder services can be run over several technologies. At the high end of the spectrum, electronic dispensaries in the home can provide alerts to carers for follow up if drugs are not dispensed regularly as part of a remote patient monitoring portfolio. Reminders can also be delivered by text message, email or phone – indeed various text message trials are underway in the NHS, and have proven successful thus far[26]. Clearly though text messaging cannot be the exclusive medium of communication, since socially dependent patients, who need services the most, are least likely to have access to or awareness of mobile technologies. Therefore reminder services could also be adopted as part of a proactive contact centre portfolio where appropriate.

Long Term Condition Clinics/Reassessment

Traditionally clinics (such as asthma and diabetes clinics) have been run on a practice by practice level, for all patients registered with the condition. However, research has shown that, in asthma management at least, telephone clinics can be just as effective and acceptable to patients, and cost considerably less[27,28]. Such services can be made available to all, but may be most effective as an alternative to proactive management for empowered self-carers, as a form of continuing reassessment of their condition.

Meeting the challenges of implementation

All this said, it is vitally important to recognise that the barriers to implementing these services are not purely technical or theoretical – they are also practical. For example, with the institution of Payment by Results and practice-based commissioning, there are now perverse financial incentives for Acute trusts to encourage acute escalations to protect their funding source, rather than to prevent them. These incentives are perverse because they naturally conflict with the clinical aims of Acute Trusts and of the NHS, and they are also opposite to the financial incentives of Primary Care Trusts under Payment by Results. Therefore any solution to manage and prevent long term conditions will have to be based on a sound business case for the future viability of Acute trusts, which may include diversification of acute services, or even co-location of primary services in secondary care.

Furthermore, changing working practices can, if presented poorly, represent a threat to existing services and workforce, which could create conflict and resistance. Therefore clinical and workforce buy-in and involvement at the solution design stage rather than retrospectively will be crucially important to the successful implementation of any long term conditions strategy.

Similarly, consistent access to high quality patient information will be required at every stage, and therefore early and close links with Connecting for Health (formerly NPfIT) will be vital in any solution implementation. Indeed, working closely with all existing programmes and organisations that impact on the NHS, such as Shared Services Initiatives and Social Care, will be important in the delivery of service change in long term conditions.

The NHS must become a proactive health and self-care promoting service that engages patients, rather than relying on the historical model of reactive care.

Conclusions

The high and rising prevalence of long term conditions is a present and rapidly growing problem for the NHS. Even given the recent surge in funding to the Health Services, it will not be possible to either stem the tide of new long term conditions patients, or to deal with these patients effectively without a fundamental change in the philosophy of the NHS, and the way it delivers care – a shift from an illness service to a wellness service. The NHS must become a proactive health and self-care promoting service that engages patients, rather than relying on the historical model of reactive care.

In order to institute this new way of working, and the new services this will entail, the NHS needs to identify and segment patients in a way that provides a behavioural as well as a risk assessment model. It is no longer sufficient to classify patients by risk alone, since the design and implementation of new services will require patient recruitment, and recruitment implies appropriateness and effectiveness of treatment, which can only be assured by a patient's willingness and ability to comply and concord with such treatment. Only a model that acknowledges the complexity of the patient, and their motivations and barriers to act will succeed in optimising clinical outcomes at the lowest possible cost.

Once patients have been recruited, appropriate services that are proactive and focus on health promotion, education and empowerment need to be built around local patient and community needs. Such services must be designed to modify patient behaviour so as to promote healthy choices, and will therefore be extendable to health promotion services such as weight management and smoking cessation. These services will be diverse and due to their diversity, and often their technological underpinnings, will require able and understanding partners from the private sector to help deliver them – helping to meet the new Department of Health targets concerning diversity of provision. This holistic approach to long term conditions and to health promotion, re-designing clinical practice by focusing on community needs and working effectively with partners, will prove invaluable to those who adopt it.

Appendix A – References

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