



Long Term Conditions Compendium of Information

Third Edition



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Policy	Estates
HR / Workforce	Commissioning
Management	IM & T
Planning /	Finance
Performance	Social Care / Partnership Working

Document Purpose	For Information
Gateway Reference	17485
Title	Long Term Conditions Compendium of Information: Third Edition
Author	DH/Long Term Conditions
Publication Date	30 May 2012
Target Audience	PCT CEs, NHS Trust CEs, SHA CEs, Medical Directors, Directors of PH, Directors of Adult SSs, Directors of HR, Directors of Finance, Allied Health Professionals, GPs, Communications Leads, Directors of Children's SSs, Voluntary Organisations
Circulation List	
Description	This guidance updates Raising the Profile of Long Term Conditions A Compendium of Information published in January 2008. It builds on the focus about care and support for those with long term conditions
Cross Ref	Raising the Profile of Long Term Conditions - A Compendium
Superseded Docs	Raising the Profile of Long Term Conditions - A Compendium
Action Required	N/A
Timing	N/A
Contact Details	Long Term Conditions Room 2N16 Quarry House Quarry Hill Leeds LS2 7UE
For Recipient's Use	

Long Term Conditions Compendium of Information

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Prepared by: Long Term Conditions Team

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First published 30 May 2012

Published to DH website, in electronic PDF format only.

<http://www.dh.gov.uk/publications>

Executive Summary

This is the third compendium of information on long term conditions (LTCs) which aims to provide the most up to date data together with a range of case study examples of excellence and innovation from across the country.

With increasing prevalence of LTCs, in particular people having two or more conditions, and the financial pressures facing the NHS in the coming years, doing more of the same will not be good enough. The information in this compendium demonstrates why there needs to be a continued emphasis in this area and showcases some of the excellent examples of good practice taking place up and down the country.

"People with long term conditions can and do self manage complex medical regimes every day including medicine taking, self injecting and dressing wounds as well as dealing with their many challenges of everyday living. They need help to have the confidence and knowledge to know what they can do effectively and safely for themselves and when to seek professional help. The Compendium should help both people with long term conditions and health care professionals to deal with and identify different ways of coping with the multiplicity of problems they face including when to seek professional help".

**Dr Patricia Wilkie President and Chairman
N.A.P.P.(National Association for Patient Participation)**

You can use this information to motivate, to challenge and to lead the transformational change across systems and influence the change culture needed to offer care and services that support people with LTCs to get the most out of their lives.

A long term condition (LTC) is a condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies.

People with long term conditions continue to see variation in care and services across the country. They are intensive users of health and social care services, including community services, urgent and emergency care and acute services. The numbers speak for themselves, for example:

¹People with long term conditions account for:

- 50% of all GP appointments
- 64% of outpatient appointments
- 70% of all inpatient bed days
- In total around 70% of the total health and care spend in England (£7 out of every £10) is attributed to caring for people with LTCs
- This means that 30% of the population account for 70% of the spend

²People with long term conditions consistently say:

- They want to be involved in decisions about their care – they want to be listened to
- They want access to information to help them make those decisions
- They want support to understand their condition and confidence to manage – support to self care
- They want joined up, seamless services
- They want proactive care
- They **do not** want to be in hospital unless it is absolutely necessary and then only as part of a planned approach
- They want to be treated as a whole person and for the NHS to act as one team

LTCs are not just a health issue they can have a significant impact on a person's ability to work and live a full life. People from lower socio economic groups have increased risk of developing a LTC – better management can help to reduce health inequalities. **Despite strides forwards there are still huge challenges.**

Patients universally say that they wish to be treated as a whole person and for the NHS to act as one team³. Despite this, those people who have more than one condition, particularly older people, face an increasingly fragmented and 'specialised' response. It is clear that LTC 'needs' transcend the organisational boundaries of social, primary, community and secondary care.



"If you consider the overwhelming evidence on long term conditions, people's views about how we can improve services and the need to do this more efficiently - then delivering more of the same is not an option. Preventive, personalised, integrated and innovative approaches must become the norm to transform people's lives and achieve better quality and productivity."

Paul Burstow Minister of State for Health Services

LTCs is one of the priority Quality, Innovation, Productivity and Prevention (QIPP) workstreams which promotes an evidence based LTC generic care model. The workstream is based on the three drivers risk profiling, neighbourhood care teams, self care/shared decision-making. The QIPP challenge, therefore, is not only to transform the way we deliver care to those people with LTCs and contribute to the current financial imperative of up to £20 billion savings, but also to set the NHS itself in a better position to remain viable for the future.

The information in this compendium speaks for itself. Long Term Conditions cost and prevalence continues to grow, doing more of the same is not an option if NHS and social care services are to be sustainable in the future.

2 Our health, our care, our say: a new direction for community services - consultation responses from people with long term conditions

3 Andrew Lansley, Health Secretary Modernising NHS 14 March 2011

Section One: Why Focus on Long Term Conditions?

The latest data from the 2010/11 Quality and Outcomes Framework (QOF) and the 2009 General Lifestyle Survey suggest that around 15m people in England have a long term condition.

- The most prevalent conditions covered by QOF are hypertension, depression, and asthma
- Some conditions do not have QoF disease registers, for example **over 5 million people report they have musculoskeletal conditions**
- The conditions rising most quickly are cancers, chronic kidney disease and diabetes
- Some of the increases in numbers of people affected may be attributed to improved and earlier diagnosis

Type of long-term condition	Number affected 2006-07	2010-11	% change
Hypertension	6,706,000	7,460,000	11%
Depression	0	4,878,000	N/A
Asthma	3100000	3,273,000	6%
Diabetes	1,962,000	2,456,000	25%
Coronary Heart Disease	1,899,000	1,878,000	-1%
Chronic Kidney Disease	1,279,000	1,855,000	45%
Hypothyroidism	1,367,000	1,667,000	22%
Stroke or Transient Ischaemic Attacks (TI)	863,000	944,000	9%
Chronic Obstructive Pulmonary Disease	766,000	899,000	17%
Cancer	489,000	876,000	79%
Atrial Fibrillation	692,000	791,000	14%
Mental Health	380,000	438,000	15%
Heart Failure	420,000	393,000	-6%
Epilepsy	321,000	337,000	5%
Dementia	213,000	267,000	25%

Table 1: Prevalence of Long term conditions on QOF disease registers

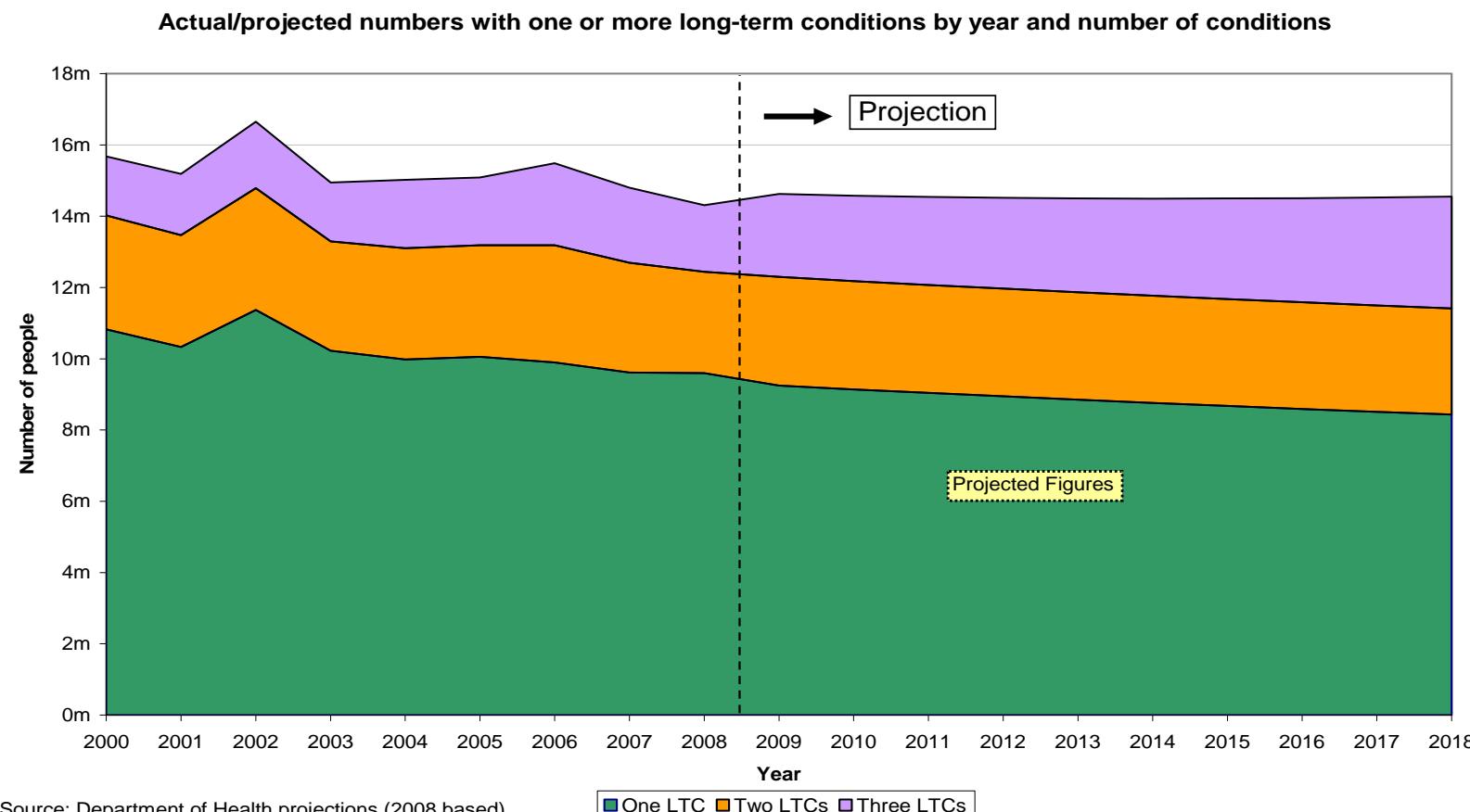
Source: Quality and Outcomes Framework, Information Centre for Health and Social Care

"The increasing prevalence of long term conditions is the biggest challenge facing the NHS now and for the future. The NHS and their partners in social care and the voluntary sector have achieved so much already, but there is still a lot to do. A huge culture change is needed to put people at the centre of decisions about their care together with a spirit of innovation that embraces new technologies. I hope that the evidence and examples of excellence shown in this Compendium will continue to inspire and motivate everyone involved in making a difference to the lives of people with long term conditions"

Miles Ayling, Director of Innovation and Service Improvement, Department of Health



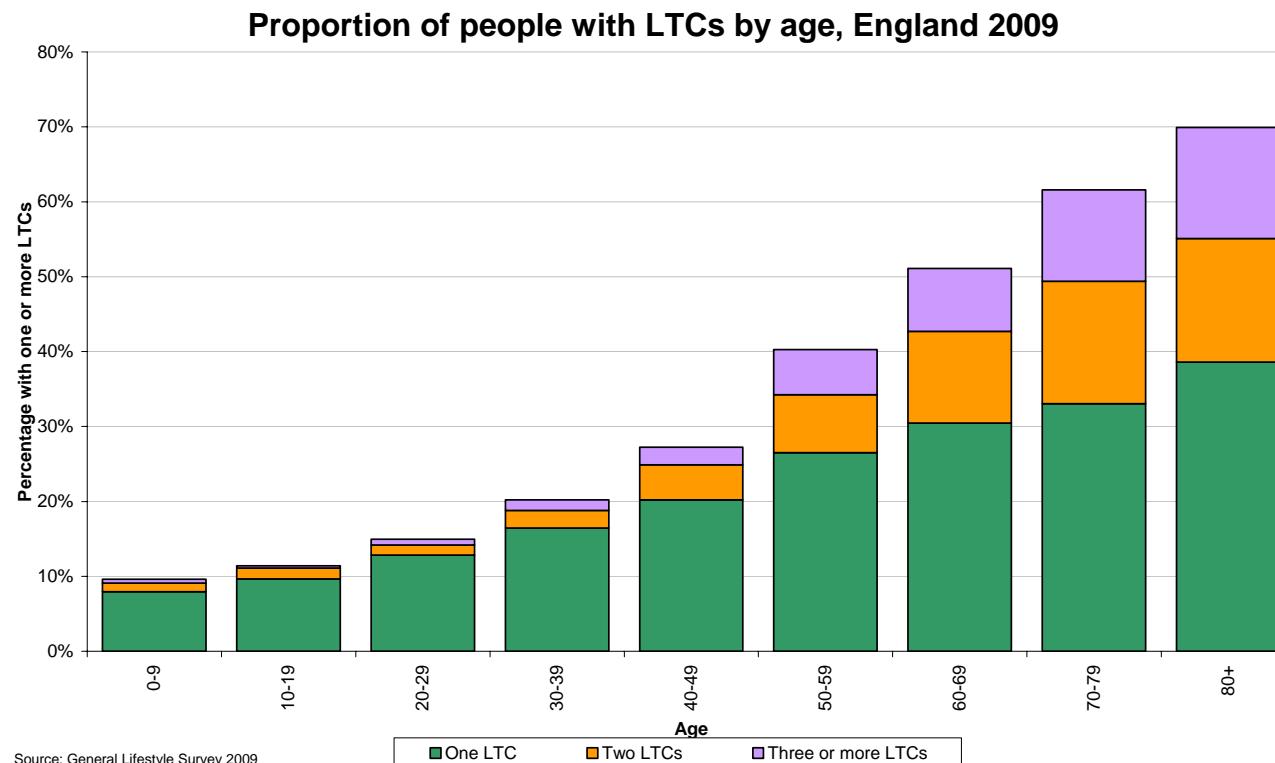
The number of people with one long term condition is projected to be relatively stable over the next ten years. However, those with multiple LTCs is set to rise to 2.9 million in 2018 from 1.9 million in 2008.



The additional cost to the NHS and social care for the increase in co-morbidities is likely to be £5 billion in 2018 compared to 2011. Plans need to be put in place now to address the health and social care issues facing people with multiple long term conditions.

The LTC QIPP workstream (see Section 2) promotes a care model which recognises that the greatest increases we will see are in the numbers of people living with co-morbidities. This must drive service design to meet patient need but ensure that the current disease pathway is still important with an appropriate response built in. Therefore, a holistic and generic view of health and wellbeing should be taken for LTC care.

Age is a major factor in prevalence of LTCs but also in those who have multiple LTCs.



"This strong and comprehensive evidence base shows us why status quo is not an option."
Sir John Oldham, National Clinical Lead for Lead Quality and Productivity, Long Term Conditions and Urgent & Emergency Care QIPP Lead

- 14% of those aged under forty report having an LTC
- 58% of those aged 60 and over report having an LTC, with 25% of over 60s having two or more

By 2034 the number of people aged 85 and over is projected to be 2.5 times larger than in 2009, reaching 3.5 million and accounting for 5% of the population. Plans need to be put in place now to address the growing needs of these people.

It is clear that the NHS, as currently configured for long term condition care, is not sustainable in the face of this projected future increase in co-morbidity and the level of need predicted.

The model of care, which QIPP promotes, seeks to address this. The approach supports self care/shared decision making to treat patients holistically regardless of their age or condition(s) whilst enabling specialist skills to impact on the patient when necessary as part of an integrated team.

Conditions by age: generally prevalence increases with age, though notably asthma is fairly steady at around 4% regardless of age.

Table: Proportion of people in age bracket with condition

Type of long-term condition	Age group								
	0-9	10-19	20-29	30-39	40-49	50-59	60-69	70-79	80+
Cancer	<1%	<1%	<1%	<1%	1%	2%	2%	3%	4%
Diabetes		<1%	1%	1%	2%	5%	8%	10%	8%
Mental Health	2%	2%	2%	4%	4%	4%	3%	3%	3%
Epilepsy	<1%	<1%	1%	1%	1%	1%	1%	1%	<1%
Stroke or Transient Ischaemic Attacks	<1%	<1%	<1%	<1%	<1%	<1%	1%	2%	2%
Hypertension	<1%	<1%	<1%	<1%	3%	8%	13%	16%	14%
Chronic Obstructive Pulmonary Disease	<1%	<1%	<1%	<1%	<1%	1%	2%	2%	2%
Asthma	4%	4%	3%	4%	4%	4%	5%	5%	5%
Musculoskeletal problems	1%	1%	3%	6%	11%	19%	22%	30%	37%
Coronary Heart Disease	<1%	<1%	<1%	1%	2%	5%	10%	13%	15%

Source: General Lifestyle Survey 2009

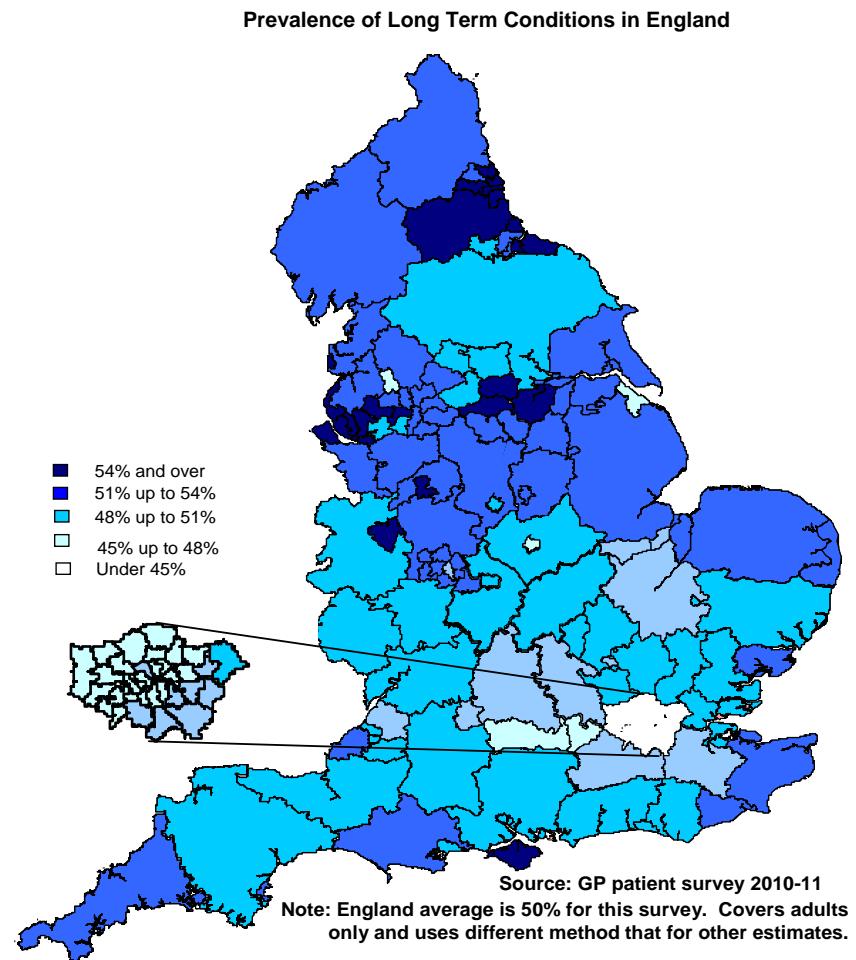
The two key factors for developing a LTC are lifestyle and ageing. Prevention, delaying onset and slowing progression of long term conditions can happen through improved public health, messaging/targeting personalised care planning, information and supported self care. It is important that the wider population is supported to take more responsibility for it's own health.

LTC QIPP is also working to support the maximisation of self care and shared decision making by stimulating and supporting a transfer of power and knowledge to patients. This requires a cultural shift for both patients and clinicians but is essential if the importance and value of self care and patient education are to be understood and seen as an integral element of LTC management.

It is important for organisations to commission and deliver age appropriate services and not to discriminate unlawfully on age grounds.

There is significant variation across England in the prevalence of LTCs

One of the three key drivers of the LTC QIPP workstream is to spread and embed the use of risk profiling. This will ensure that commissioners understand the needs of their population and can better manage those at risk.

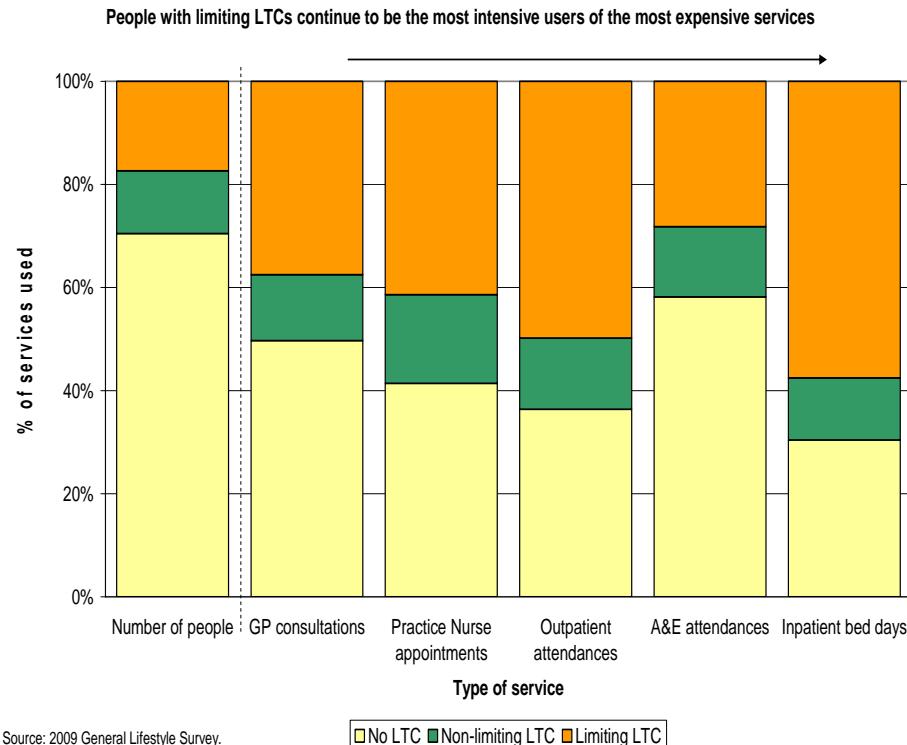


While prevalence of long term conditions is linked to age and socio-economic status, there are a number of other associated factors that are also linked. Understanding the make up and needs of the local LTC population is vital. Commissioners have access to rich data sources, which can be better used. Tools that utilise this data such as risk stratification tools and clinical dashboards are available to support commissioners (see Annex A page 51)

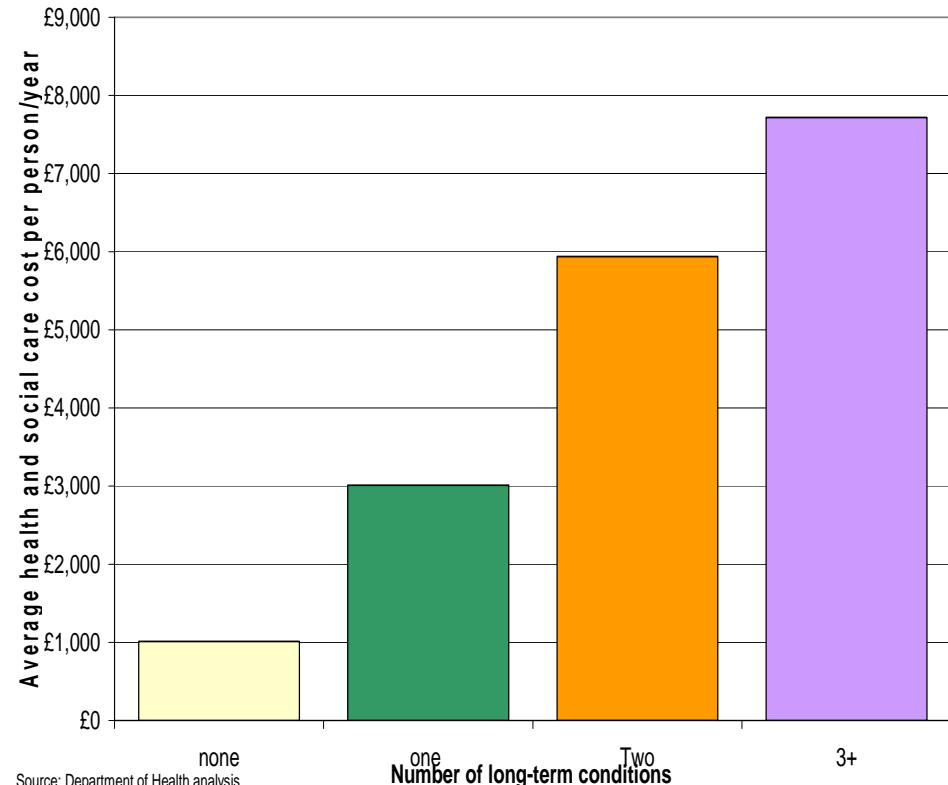
"The most crucial issue in the management of long term conditions is how we better support people to self care. Indeed, it is an urgent necessity if we want to put patients in control of their conditions and if the NHS is to balance its books. Ivan Illich in 'Medical Nemesis' said "the greatest future achievement in medicine will not be some new technological achievement, but if we can better support people to look after themselves."

Dr Michael Dixon, Chair NHS Alliance

People with limiting LTCs continue to be the most intensive users of the most expensive services. As a consequence, the average cost of health and care for someone with long term conditions is much higher than those without.



Source: 2009 General Lifestyle Survey.

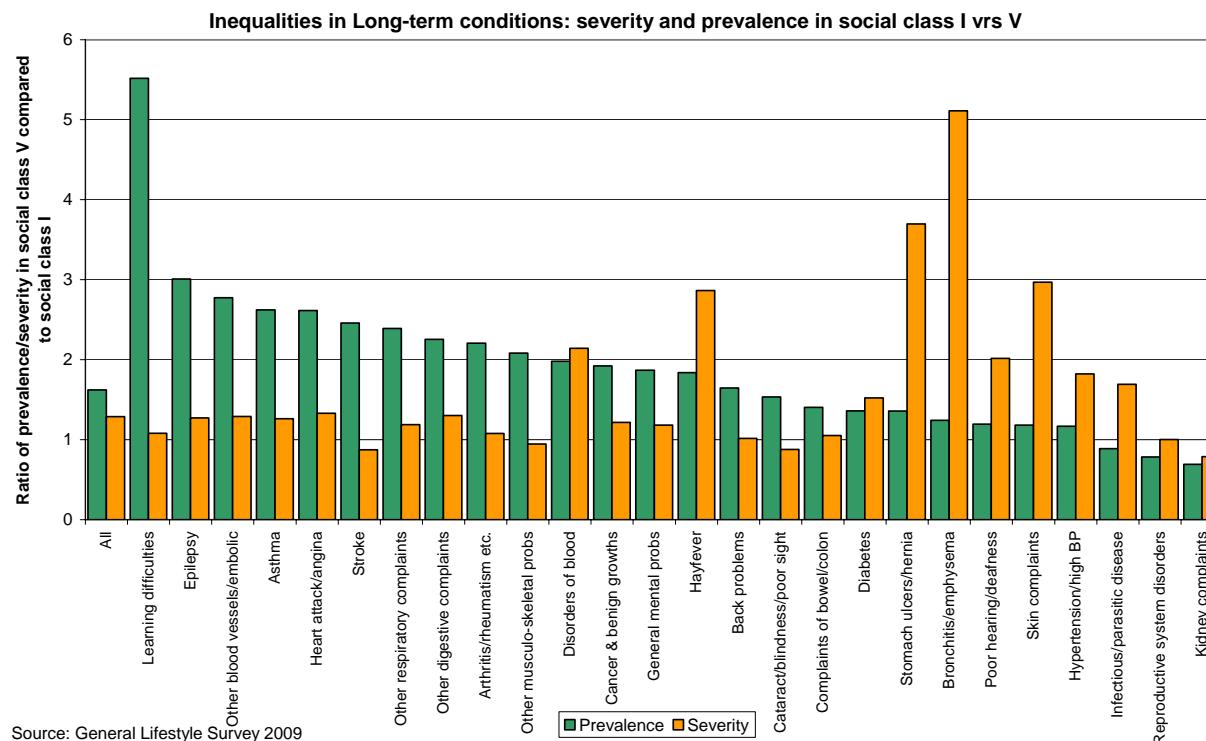


Delaying onset of developing a LTC and slowing progression is part of a LTC generic model of care. Implementing this can have a positive impact not only on people's lives but on reducing health and social care costs.

The LTC QIPP workstream focuses on improving the quality and productivity of services for these patients and their carers so they can access higher quality, local, comprehensive community and primary care. This will in turn, slow disease progression and reduce the need for unscheduled acute admissions by supporting people to understand and manage their own condition(s).

Social class – Compared to social class I, people in social class V have 60% higher prevalence of long term conditions and 30% higher severity of conditions, though this varies significantly by condition

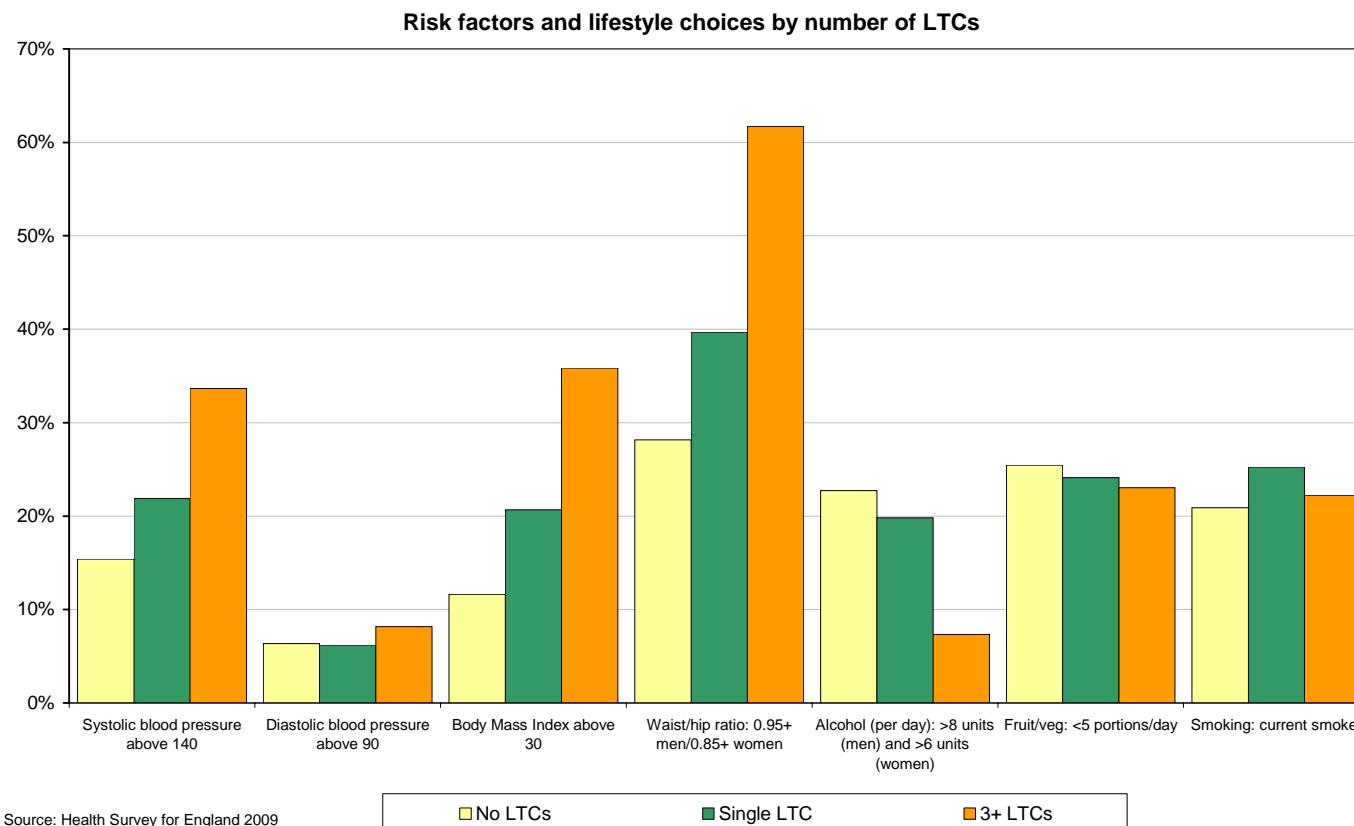
Respiratory conditions tend to have low inequalities for prevalence, but high for severity, whereas learning disability and epilepsy have higher prevalence inequalities



Better LTC management with supported self care can make a real difference to narrowing the health inequalities gap. Appropriate information that takes account of different levels of literacy, communication and comprehension ability can help people to self-care. The Expert Patient Programme Social Return on Investment⁴ study provides important evidence that targeted self management programmes can have positive results across wider society. As well as savings for the health sector in the ratio of £3.00 for every £1.00 invested there is a wider social return in the ratio of up to £6.00 for every £1.00 invested, depending on the type of programme.

⁴ <http://www.exPERTpatients.co.uk/sroi-report>

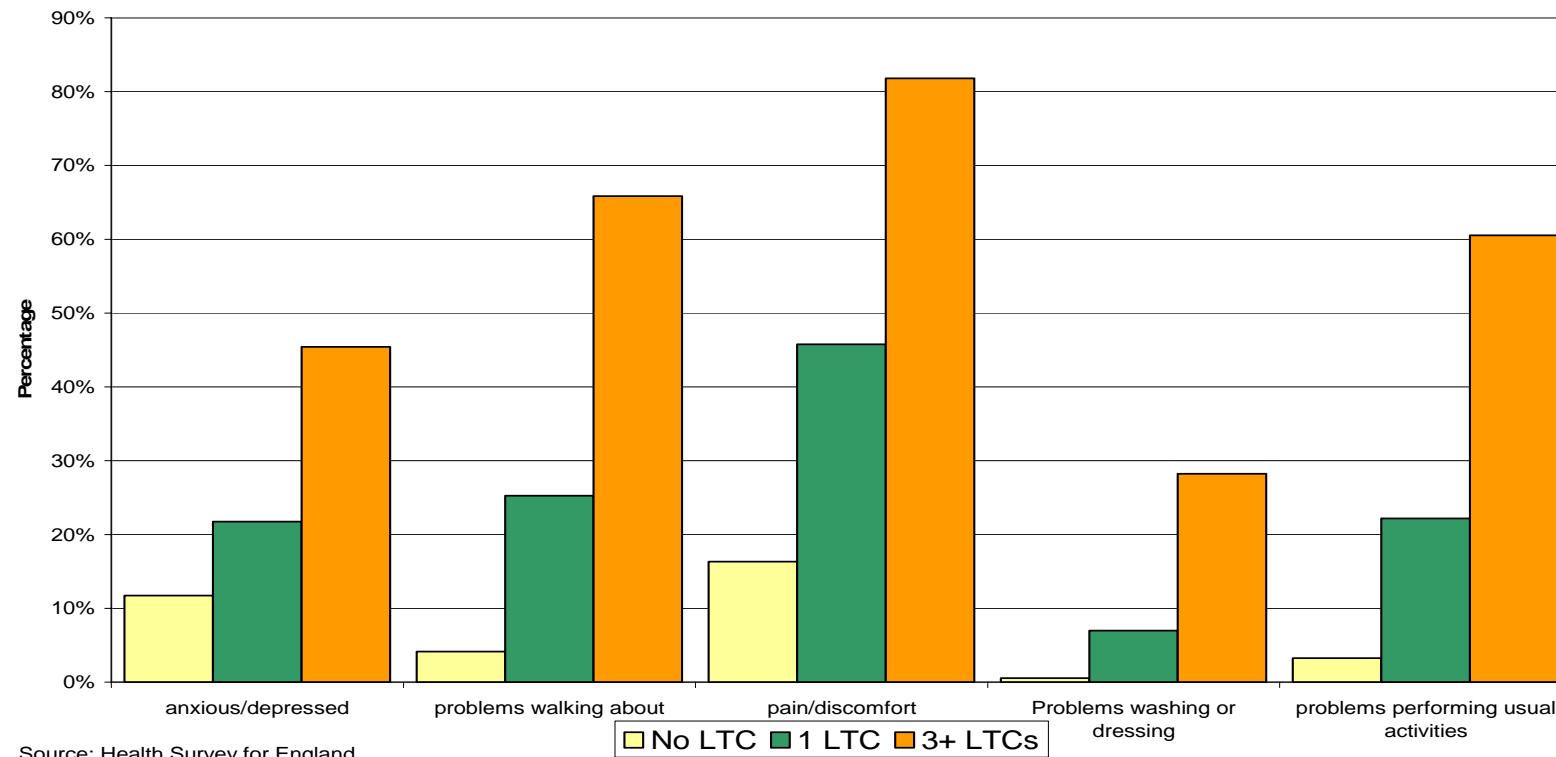
People with at least one LTC are more likely to have risky health behaviours: people with a LTC are more likely to have high blood pressure and be obese, though it is unclear the direction of causation



Social marketing techniques and market segmentation, used with other techniques such as risk stratification can also be powerful for identifying need, targeting resources, communications and supporting behaviour change.

The use of risk profiling tools being promoted through the LTC QIPP workstream will help to prevent disease progression and will allow for interventions to be targeted and prioritised more effectively.

Having a long term condition usually reduces people's quality of life, particularly through having chronic pain. People with co-morbidities can find their ability to live their lives severely affected.



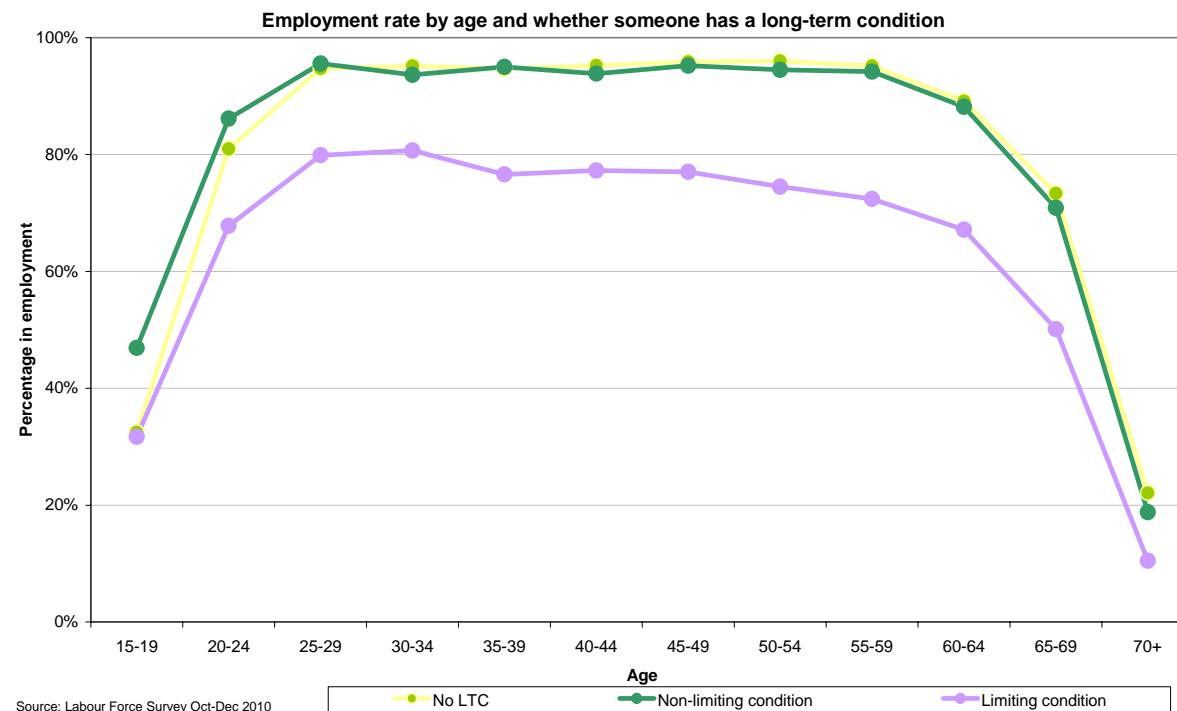
Source: Health Survey for England,

The information about the different aspects of quality of life is taken from an internationally used survey tool – the EQ5D⁵. Having a LTC can affect all aspects of physical and mental wellbeing and people with more than one long term condition are significantly more affected. In particular, almost half of all people with a LTC report moderate or extreme pain, rising to 80% of people with three or more conditions.

This reinforces the need to adopt a generic care model which acknowledges and addresses all the health and wellbeing needs of an individual.

⁵ Standardised instrument for use as a measure of health outcome for use in postal surveys, in clinics and face-to-face interviews

Those with a LTC have an increased likelihood of not working – those with a limiting long term condition are half as likely to have a job than those with a non-limiting LTC or with no LTC



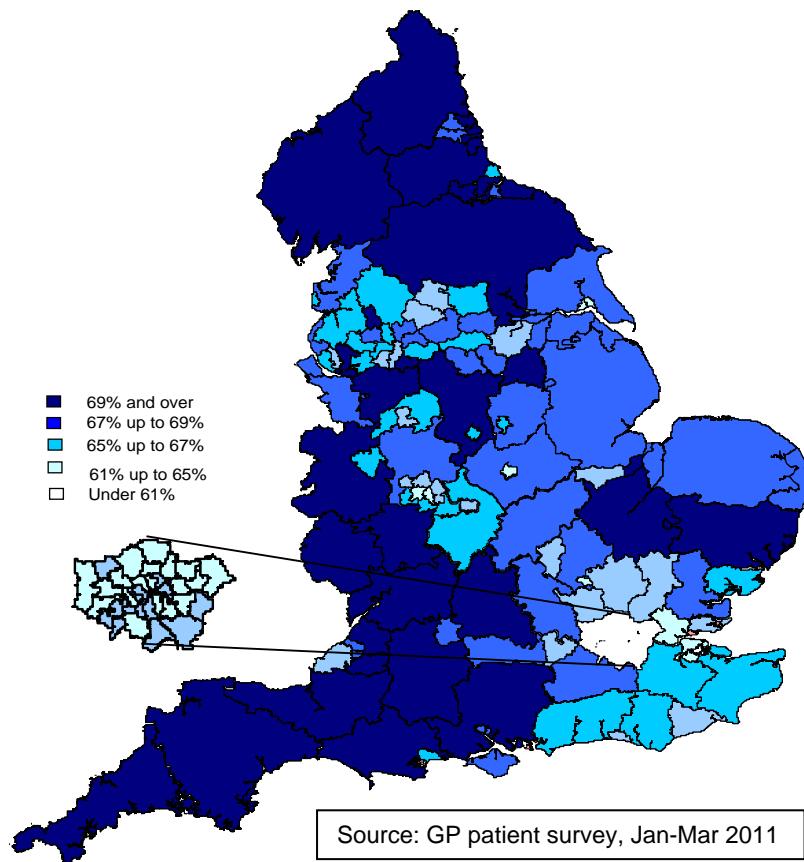
Over half of people with a LTC say that their health is a barrier to the type or amount of work they can do, rising to over 80% when someone has three or more conditions⁶.

Where having a LTC affects people's day to day activity, it significantly reduces their chance of being in work

Being out of work is detrimental to health. Viewing a person with a LTC holistically means supporting wider needs such as a desire to return to work. This could be an individual's care planning goal and may link with them being able to better self care. It could for example motivate someone to stop smoking or lose weight. These inter-related care planning goals can support behaviour change and lead to overall better health and well being.

⁶ Labour Force Survey 2009

There is variability in the proportion of people with an LTC having a care planning discussion

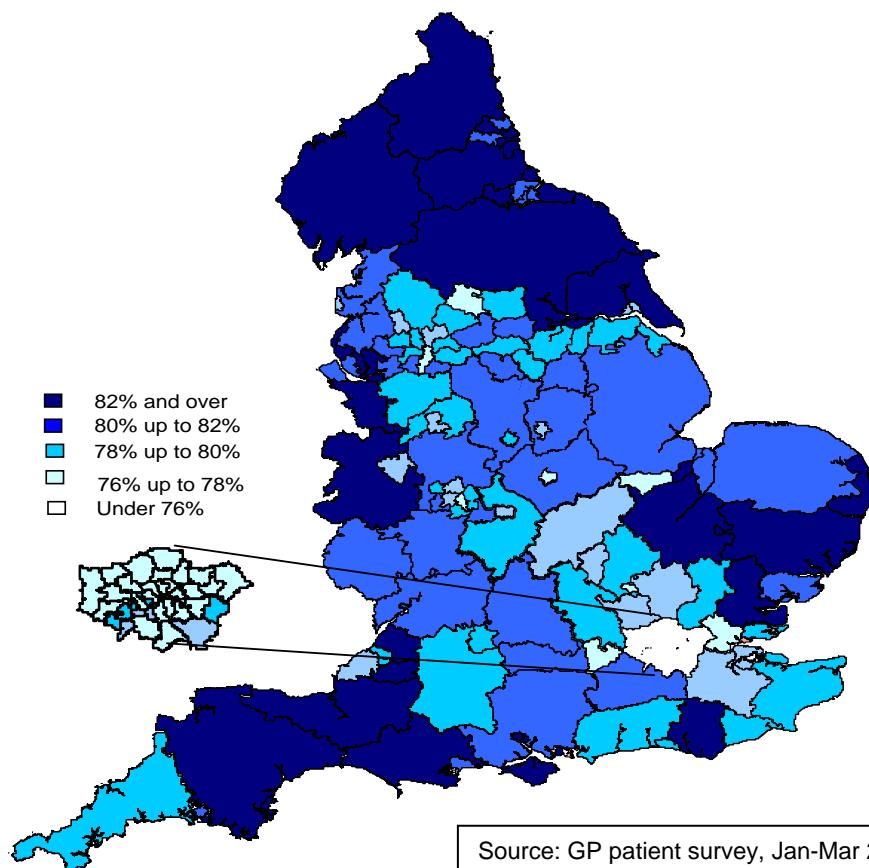


On average 66% of people in England report having agreed a care plan to manage their condition. Of those 96% report an improvement in their care.

This varies between 77% and 86% across the country with PCTs in London and the South East, and other urban areas tending to have lower rates of care planning discussions than elsewhere in the country

Personalised Care Planning means involving people in decisions about their care with access to all the information they need to help them make those decisions – “no decision about me without me”. The emphasis going forward is that discussions about managing conditions become part of high quality, personalised care planning and that this becomes the norm for everyone with a LTC.

Those who say they feel supported to be independent and in control of their condition is variable across the country.



- On average 79% of people in England report having enough support to be in control of and manage their condition
- This varies between 66% and 86% across the country with PCTs in London, the midlands and northern urban areas tending to have lower rates of patients feeling supported than others

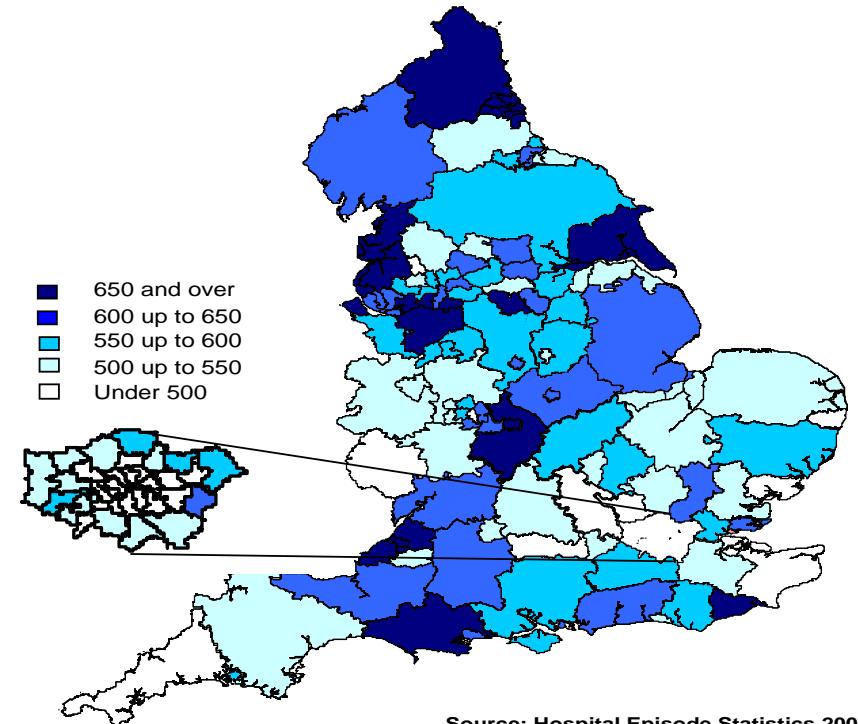
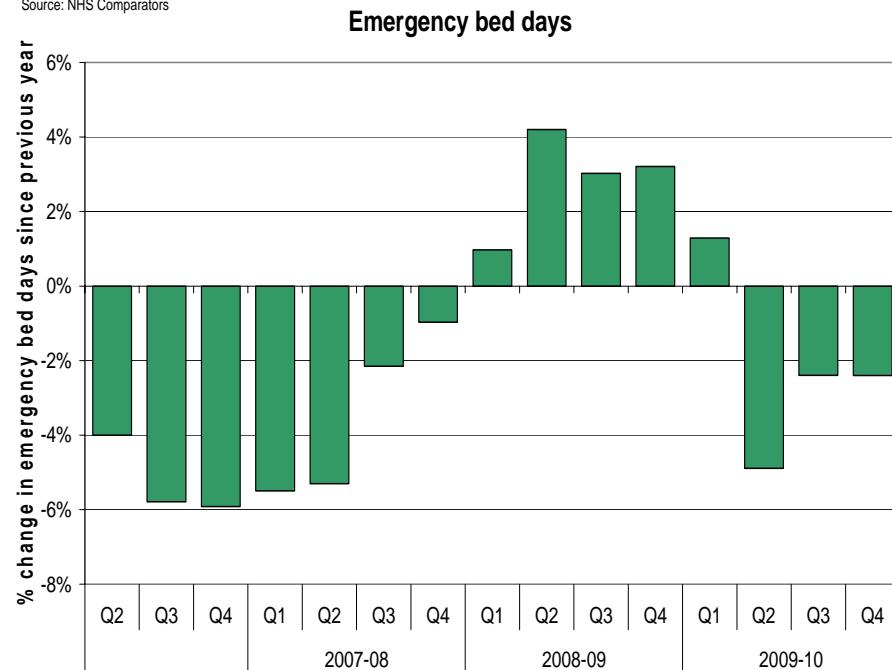
"Supporting people to self care should start by supporting them to understand and accept their condition. By acknowledging that they have a LTC, individuals can begin the journey of developing knowledge, skills and confidence that can help optimise their quality of life and even slow the progression of their underlying clinical condition." Dr Alf Collins – Consultant in Pain Management - Somerset

The ultimate aim is that people with LTCs feel they are confident and able to manage their condition(s). Supported self care must become the norm if we are to achieve this.

Empowering patients to maximise self-management, shared decision making and choice is one of the three key drivers of the LTC QIPP workstream. This includes ensuring that patients are offered a care plan and that both patients and their carers have access to the appropriate information about how to manage their condition. There needs to be a systematic transfer of knowledge to patients for this to happen.

After a number of years of falling emergency bed days, the number rose in 2008-09, but has fallen back in 2009-10. The variation across England has not changed in last 5 years

Source: NHS Comparators



Source: Hospital Episode Statistics 2009-10

The LTC QIPP programme aims to reduce this variation in delivery of service. The workstream is working to co-produce locally driven activity that will address local needs and priorities to reduce variation and increase quality of care across the country. The workstream seeks to reduce unscheduled hospital admissions by 20%, reduce length of stay by 25% and maximise the number of people controlling their own health through the use of supported care planning.

These are good proxy measures of how well LTCs are being managed. Interventions such as integrated neighbourhood care teams, holistic case management, virtual community wards, rapid response teams, risk stratification, supported self care, one to one telephone coaching and use of assistive technologies (telehealth and telecare) can all prevent unnecessary, unscheduled admissions. Good discharge planning is crucial to prevent avoidable readmission.

Section Two: Policy Context

The Health and Social Care Act 2012 is a crucial part of the Government's vision to modernise the NHS so that it is built around patients, led by health professionals and focused on delivering world-class healthcare outcomes. The Act contains provisions covering five main themes, one of which is strengthening commissioning of NHS services through clinical commissioning. Clinical commissioning will empower NHS professionals to improve health services for the benefit of patients - including those with LTCs - and communities, through securing continuous improvements in the quality of services commissioned; reducing inequalities; enabling choice and promoting patient involvement.

"Commissioning is at the heart of improved long term conditions management. Clinical commissioning groups will play a vital role in ensuring that people with long term conditions are involved in designing services that fit around them and meet their wider needs. Through clinically-led commissioning we want to ensure there is emphasis in this important area and that people with long term conditions experience high quality outcomes, have maximised choices and that we secure efficient use of NHS resources."

Dame Barbara Hakin, National Managing Director of Commissioning Development, Department of Health

Personalisation, information, choice, supported self care, shared decision making, integration and cross boundary working must become the norm for people with LTCs. These approaches are core to a generic long term conditions model which will continue to be implemented. A generic long term conditions model is an evidence based approach for improved long term conditions management adapted for use in the NHS from the Chronic Care Model developed in the late 1990s by Ed Wagner in the USA. The model has been promoted in England since 2005.

A LTC generic model has the following key elements that should be adopted for all conditions and care pathways:

- Commissioners understanding the needs of their populations and managing those at risk using **risk prediction** techniques
- Supporting people to be more confident and in control of their condition using **information** and **self care** as part of **personalised care planning**
- Providing integrated neighbourhood care teams and **joined up and personal services** particularly in community and primary care and working closely and effectively with social care
- Strong **professional and clinical leadership** and **workforce development** to deliver new models of care
- Using new technologies – ie , information from Whole System Demonstrator Programme on the benefits of **telehealth** and **telecare** to support people to be more independent and in control.

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This model aims to support people to be involved, informed, independent and in control of their condition(s). This approach works equally for people with single conditions or multiple co-morbidities. It is also equally effective for physical and mental health issues and is applicable to people of all age groups including the frail elderly.

Measuring Improvements A focus on high-level outcomes for people with long term conditions

The NHS Outcomes Framework will help patients, public and Parliament understand how well the NHS overall is doing in terms of improving health outcomes. It moves away from top down targets and instead intends to focus on a set of national outcomes using publicly available data. The Framework contains overarching indicators for five key domains together with improvement areas in each of those domains.

Domain 2 of the Outcomes Framework is “**Enhancing the quality of life for people with long term conditions**” which seeks to capture how successfully the NHS is supporting people with LTCs to achieve positive health and well being outcomes. The overarching indicator “health related quality of life for people with LTCs” aims to better understand whether this is increasing over time. The indicator uses the EQ-5D tool, which is a patient reported outcome measure (PROM) measuring health status or health-related quality of life. Improvement areas focus on the generic outcomes that matter to most people with LTCs based on responses to the consultation. These are:

Ensuring people feel supported to manage their condition – a measure of the proportion of people who feel supported to manage their condition

Improving functional ability in people with a long term condition(s) - measured through employment of people with LTCs

Reducing time spent in hospital by people with LTCs - measured using data on unscheduled admissions for chronic ambulatory care sensitive conditions and unscheduled admissions for asthma , diabetes and epilepsy in under 19s

Enhancing quality of life for carers – measuring health related quality of life for carers

Enhancing quality of life for people with mental illness - measuring employment of people with mental illness

These improvement areas will be supported by **Quality Standards** developed by the National Institute for Health and Clinical Effectiveness (NICE).

"Now, more than ever before, the NHS has to achieve value for money and the best possible quality so that patients get the greatest benefit. The Quality, Innovation, Productivity and Prevention (QIPP) programme is all about ensuring that each pound spent is used to bring maximum benefit and quality of care to patients"

Jim Easton National Director for Improvement and Efficiency, Department of Health

Future Development

A LTCs outcomes strategy is being developed aimed at improving outcomes for all people with LTCs. The strategy will look at all of the aspects that impact on the lives of people with LTCs, and outline how the key players (government departments, local authorities, charities and individuals) can act in future in order to reduce LTC incidence, and improve outcomes for those with LTCs.

We know that the same people who are disadvantaged across the wider social determinants of health are also those who are likely to develop a LTC. As a result we want to identify those points in people's lives where intervention, in order to target spending at the times, and in the locations, where it can have most impact. By taking a life course approach, we hope to be able to reduce the incidence of LTCs, delay their onset, mitigate secondary complications, and better support people with LTCs

The Quality and Productivity Challenge (QIPP) and Long Term Conditions

Improved LTC management is one of the priority QIPP workstreams with huge potential to both increase quality **and** make efficiency savings. But embedding a generic LTC model needs to happen more quickly to achieve these benefits. There is an imperative now to move things forward. The NHS, social care and third sector partners have made significant strides forward, putting in place a foundation to build upon. The case studies in section two are testimony to this - but there still remains much to be done.

The QIPP workstream is based on 3 drivers which are the fundamental features of all best practice LTC care programmes both here and abroad. The workstream promotes a generic care model that will achieve these results and recognises that the greatest increases will be seen in the numbers of people living with co-morbidities. Therefore, an holistic and generic view of health and wellbeing, needs to replace the current disease pathway approach taken to LTC care. Where a LTC model, based on the 3 key principles (shown below), has been effectively applied, the best sites have been able to reduce unscheduled admissions by 20%. The workstream aims to support the NHS to achieve similar results by 2014.

RISK PROFILING - Using validated risk profiling to support commissioners to understand the needs of their population and manage those at risk. A risk prediction tool will identify a list of patients (or virtual ward) that are at high and medium to high risk of accessing healthcare services. This will assist in preventing disease progression and will allow for interventions to be targeted and prioritised.

NEIGHBOURHOOD CARE TEAMS - Creating a functionally integrated generic care team at a locality level including community services, AHP's, social services, specialist nurses and linked to GP practices. These integrated health and social care teams are based around a locality (or neighbourhood) and provide joined up and personalised services. These generic teams pull in specialist services when necessary, but treat a patient holistically, regardless of their condition(s). Each patient has a key worker within this team who co-ordinates their care and acts as the point of contact.

SELF CARE / SHARED DECISION MAKING - Empowering patients to maximise self-management and choice, through shared decision making and motivational interviewing. This includes ensuring that: (1) patients engage in shared decision making to co-produce a care plan, (2) both patients and their carers have access to the appropriate information about how to manage their condition, (3) patients are active participants in all decisions about their care ('no decision about me without me') and (4) that patients have access to their medical records. This requires a cultural shift for both patients and clinicians, whereby the importance and value of self care and patient education are truly understood and where shared decision making and supported self care are seen as integral elements of LTC management.

There are tough choices ahead, but every saving made will be reinvested in frontline line services to meet the rising cost pressures facing the NHS from an ageing population and to fund new drugs and technologies.

Measures of the LTC QIPP workstream

The LTC QIPP workstream will result in better management (including self-management) of patients with Long Term Conditions. This will result in a slower disease progression, fewer planned and unscheduled acute episodes and shorter lengths of stay for patients with LTCs. This in turn will reduce demand for services in the acute sector which will enable Acute Providers, working with commissioners to reduce the costs of the services they provide.

The measures in the first phase of this workstream will be the percentage of unscheduled admissions and the length of stay for the cohort of patients in the chosen pathways. These proxies indicate whether the whole care package is operating effectively – they will provide an insight into how well LTCs are being managed and how well the system is supporting a generic care model. This data is already collected and measured using hospital episode statistics. The measurement therefore, imposes no additional burden.

In addition, a qualitative measure will be used in the form of a validated patient questionnaire (LTC6) that identifies whether care planning and supported self care have been operational and effective. This measure will be solely used for the workstream and is designed to augment other nationally collected data.

The “LTC 6”

This questionnaire is a key measure of whether people with LTCs feel they are receiving personalised, coordinated services and that they are fully engaged in decisions about their care. These measures should give a good indication of patient experience and whether information, support for self care and choice are being delivered as part of personalised care planning. This is being used by the LTC QIPP teams but can be adopted by any organisation (including GP Consortia) across the country as a key outcome measure for improved LTC management.

The LTC 6

- 1. Did you discuss what was most important for *you* in managing your own health?**
- 2. Were you involved as much as you wanted to be in decisions about your care or treatment?**
- 3. How would you describe the amount of information you received to help you manage your health**
- 4. Have you had enough support from your health and social care team to manage your health?**
- 5. Do you think the care and support you receive is joined up and working for you**
- 6. How confident are you that you can manage your own health?**

Remember.....

The greatest untapped resource is patients themselves – if they are supported by health and social care professionals to have the confidence to take control and manage their conditions better – slowing disease progression and reducing reliance on services

Section Three: Long Term Conditions and Mental Health

There is a strong link between physical long term conditions and psychological distress/disorder. Addressing psychological need can improve outcomes and reduce health care consumption. NICE recommends the use of psychological interventions for people with long term conditions.

Mental health problems are much more common in those with physical illness. Compared with the general population, people with diabetes, hypertension and coronary artery disease have double the rate of mental health problems, and those with chronic obstructive pulmonary disease, cerebro-vascular disease and other chronic conditions have triple the rate. People with two or more long term conditions are seven times more likely to have depression⁷. Severe mental health disorders such as schizophrenia and bipolar disorder and less severe mental health problems such as depression and anxiety are all considered to be primary long term conditions. People with these conditions are more likely to develop other long term conditions such as diabetes or cardio vascular disease.

Further, untreated depression leads to worse health outcomes and increased health care spending among those with long term conditions:

- Co-morbid depression is associated with a 50% to 75% increase in health spending among diabetes patients (Simon 2005)
- Those with cardiac problems are three times more likely to die of these causes if they also suffer from depression than if they do not (Frasure-Smith et al 1999)
- Research has shown that people with heart disease are more likely to suffer from depression, and people with depression are at greater risk of developing heart disease (Nemeroff 2000).

Since 2008 the delivery of talking therapies has focused largely on the full roll out of the Improving Access to Psychological Therapies (IAPT) programme. This aims to offer those with depression and anxiety disorders evidence-based, NICE approved therapies. By March 2011, 95% of all PCTs in England's were able to offer IAPT compliant services with capacity to treat on average around 8% per annum of the estimated morbidity. By the end of 2014/15 plans are in place for sufficient capacity in all local health economies to address a minimum of 15% of local morbidity (900,000 patients) per annum.

⁷ NICE (2009) Depression in adults with a chronic physical health problem: treatment and management <http://www.nice.org.uk/nicemedia/pdf/CG91FullGuideline.pdf>

People with a physical LTC should be assessed for the presence of depression and anxiety as part of their personalised care planning process. This can help reduce inequalities, support people with LTCs to have a better quality of life, and deliver important cost savings to the NHS.

At the same time, severe mental illnesses such as schizophrenia bipolar disorder and personality disorder can be regarded as primary long term conditions.

The LTC QIPP workstream is working to ensure that mental health needs are fully recognised and addressed as an integral part of a person's care package.

Medically Unexplained Symptoms

Medically unexplained symptoms (MUS) are physical symptoms that have no currently known physical or pathological cause. People with MUS present commonly to the NHS. Analysis of 2008/09 NHS figures show that they account for as many as one in five new consultations in primary care, 7% of all prescriptions, 25% of outpatient care, 8% of inpatient bed days and 5% of A&E attendances (Birmingham et al, 2010). **It is estimated that the NHS spends £3 billion a year on MUS⁸.**

For people with medically unexplained symptoms, contacts with primary care physicians may be at least 50% greater than in the general population and they may also have 33% more secondary care consultations (Moriss and Gask, 2009). However, identification of people presenting with MUS remains a challenge.

A study undertaken in Germany, looking at inpatients treated for somatoform disorders, indicated that the costs of Cognitive Behavioural Therapy (CBT) were more than offset by a reduction in health care utilisation, and in a two-year follow up of this study, researchers also found a 35% reduction in work loss days (Hiller et al 2003).

The symptoms often cause significant psychological distress, and up to 70% of people with MUS also have depression and/or other anxiety disorders. This is of significance because these mental health disorders are detectable and treatable, irrespective of the explanation for the physical symptoms.

⁸ Birmingham S, Cohen A, Hague J, Parsonage M (in press) The cost of somatisation among the working-age population in England for the year 2008/09 Mental Health in Family Medicine

Long Term Conditions Compendium of Information: Third Edition

Talking therapy services have been shown to improve outcomes for people with LTCs and mental health issues, and for those with MUS. Integrating access to talking therapies into the care pathways for those who suffer with these conditions will:

- improve outcomes; and potentially secure long term cost savings by reducing the heavy use of NHS resources by people with these conditions (particularly in an acute inpatient setting).

Case Study: Cognitive Behavioural Therapy (CBT)

A training programme for nurses in cognitive behavioural therapy (CBT) was implemented and evaluated at St Christopher's Hospice in South-East London. The aim was to see whether palliative care nurses could be taught to deliver basic cognitive behavioural therapy techniques and so reduce symptoms of anxiety and depression. A randomised controlled trial (RCT) was undertaken to evaluate the effects of the training programme.

The study aimed to test:

- a) The effect of the training on the nurses' knowledge and competency in CBT
- b) The effect of training on the patients' symptoms of depression and anxiety.

Key elements of the intervention

- Nurses were randomly allocated to receive training in CBT or continue their usual practice. Seven nurses continued practising as usual and eight received training.
- The intervention consisted of a structured training and supervision package. Nurses attended a two-day introductory workshop, seven 1-day workshops and a refresher day, followed by weekly supervision groups with an expert in CBT for people with cancer.
- Training focused on how to apply CBT to commonly occurring problems, such as helplessness, hopelessness, panic, worry, insomnia and fear of death and dying. The aim was to enhance communication during the consultation and enable nurses to improve patients' adjustment to cancer, promote effective coping and reduce psychological distress.

Impact

At the end of the trial, the nurses were rated for CBT knowledge and competency. Levels of competency were considerably higher among the nurses who had been trained, showing that clinicians with no mental health training can learn and apply basic CBT techniques.

Eighty patients with probable depression or anxiety entered the trial. Due to the seriousness of their illness only 46 were well enough to complete a 6 week assessment, 36 completed the 10 week assessment and 34 continued for 6 weeks. Nurses trained in CBT reduced symptoms of anxiety in their patients significantly more than the nurses not trained in these methods. A differential effect on depression was less apparent, with the patients of both trained and untrained nurses becoming less depressed over time.

The nurses trained in CBT were interviewed after the study and it was clear that they felt they had benefited in terms of increased knowledge and skills. The comments were overwhelmingly positive, with nurses enthusing about their improved ability to assess, support and effect change in patients with psychological symptoms. They felt they had more confidence to 'stay with' difficult issues and feelings and were more able to identify and challenge negative thoughts.

'Before I might have thought, "oh dear, he's obviously distressed about his cancer and he's living alone, maybe he just needs some sleeping tablets" and he didn't actually need them'

'Now, I'm far more focussed on teasing out the main underlying problem or anxiety and then working on that specific thing'

'Even on a one-off visit in the night, the techniques are useful to identify deeper issues and deal with things, even if the visit is because of severe pain [or] nausea there is always great value in adding a conversation about thoughts/ feelings/ fears'

This training is now being disseminated across the country by an initiative supported by Marie Curie Cancer Care. For more information please visit St Christopher's Hospice website at www.stchristophers.org.uk

Section Four: Emerging Technology - Telehealth & Telecare

There are many small trials showing that appropriate use of Telehealth⁹ and Telecare¹⁰ can lead to improved outcomes and reduced admission to hospital and care homes. This in turn can improve the quality of life and deliver savings to the health and social care system. Yet take up in England has been slow, around 5,000 Telehealth users and 1.5m pieces of Telecare installed to date. One reason for slow take up has been the lack of evaluated evidence. The Department for Health in England invested in a three year programme to provide that evidence on a larger scale.

Whole System Demonstrators Programme

The Department's Whole System Demonstrator (WSD) programme is the largest randomised control trial in the world of telecare and telehealth involving over 6,000 people across 3 sites in England (PCT/LA partnerships in Cornwall/Kent and Newham) and 138 GP practices. The programme was developed to provide a robust evidence base on the benefits for patients and carers, patient outcomes, impact on use of healthcare resources, and the best ways of supporting delivery.

The Whole System Demonstrator programme has been one of the most complex and comprehensive studies the Department has ever undertaken. Six of the major academic institutions - City University London, University of Oxford, University of Manchester, Nuffield Trust, Imperial College London and London School of Economics were involved to provide information on service utilisation, quality of life, cost effectiveness, user/personal experience, organisational issues and effects on carers. The programme focused on three conditions, diabetes, COPD and coronary heart disease.

⁹ Electronic equipment to read vital health signs such as pulse, weight, respiration and blood oxygen levels and then sending those readings remotely to a health professional. The equipment can be installed in the patient's home and the readings monitored in a different location

¹⁰ Electronic equipment used in a person's home to support independent living such as personal pendant alarms worn around the neck, bed sensors to detect unexpected movements, flood alerts and door alarms

Early headline findings published by the Department on 5 December 2011 showed¹¹

- a 15% reduction in A&E visits;
- a 20% reduction in emergency admissions;
- a 14% reduction in elective admissions;
- a 14% reduction in bed days;
- an 8% reduction in tariff costs;

More strikingly, they also demonstrate a 45% reduction in mortality rates

3millionlives

Now that the WSD programme has provided the above evidence, there is a need to ensure that these technologies can be adopted by and integrated into NHS England at scale and pace. Department of Health modelling suggests the potential for £1.2bn saving over 5 years if numbers using telehealth increase to around 3 million

To achieve this level of change the Department of Health has committed to working in partnership with UK industry, the NHS, social care and professional partners in collaboration with a difference, “**3millionlives**” (www.3millionlives.co.uk) to drive up scale and bring the benefits to as many people as possible. The aim is to enhance the lives of three million people over the next 5 years by accelerating the mainstreaming of telehealth and telecare in the NHS and social care.

The introduction of telehealth and telecare is going to require significant organisational change and close working of professionals and managers in health and social care if the technology is to be deployed successfully. Health professionals will play a crucial part in ensuring this technology is used to improve service delivery and patient satisfaction. Telehealth and telecare will enable community professionals to manage their case load more efficiently, seeing people who need them and monitoring remotely those whose care is under control.

This technology is a tool through which patients can feel secure that their care is being managed effectively whilst enabling them to get on with their lives. 3millionlives is about transformational change, building services for people with long term conditions, supporting with technology where needed and building a new business models.

¹¹ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_131684

A commitment to improve the lives of 3 million people is without precedent and will not only benefit patients and the NHS but will put UK based industry into a leading position to exploit a world wide market of billions of people which could generate jobs and income for UK plc.

Examples of Benefits of Telehealth

Haris Patel is 53yrs old, has been diagnosed with Ischemic Heart Disease, Parkinson's, Peripheral Vascular Disease, Hypertension has suffered a number of strokes and is a wheelchair user.

On average, he spent at least 8-10 months a year as an inpatient in hospital. A GP and District Nurse would regularly conduct home visits. As a result of his condition he was not able to plan his life on his 'good days' due to having to stay at home for the medical support team in order to accommodate these visits and for blood pressure checks to be carried out etc.



Telehealth was installed in his home that monitors key signs of his health. His blood pressure was measured twice a day, and once a week his sugar levels and weight are reviewed, with all results being transmitted to a nursing station for clinical analysis by Matrons, his GP and Consultants.

Since Telehealth, in the last four years, he has spent three weeks as an inpatient compared to the previous average of 8-10 months spent in hospital each year. Results from Telehealth readings mean that if changes occur a GP visit or a consultant appointment can be arranged. Medications can be adjusted to better manage his condition(s) so they do not exacerbate. Unscheduled hospital admissions are consequently avoided.

The use of technology has allowed his needs as a patient to be met, whilst promoting his independence. Through his own admission, Haris claims Telehealth has changed his life completely; giving him 'full control of [his] life'. He has managed to achieve confidence and self-esteem which prior to being on Telehealth had been totally lost

Reassurance & Reminder Health Calls

There are systems available to help people manage their long term condition, for example, insulin and blood sugar levels, by making proactive calls to an existing landline or mobile telephone. A personalised health call can help people to remember to take medication, ask health questions or ensure readings are normal whilst the patient is low-medium risk.

The results collected from the health calls can help monitor their condition and identify potential patients at risk at a far earlier stage. When the patient's condition gets worse then there is the opportunity to escalate to a more advanced system. Reassurance and Reminder health calls:

- Supplement existing telehealth platforms
- Allow for managing patients across the entire 'health triangle'
- Are relatively low cost and scalable
- Are suitable for those who have low/medium risk long term conditions
- Can be used from the point of diagnosis, meaning they could prevent unnecessary hospital admissions

The health calls can act as a screening process, can support independence, increase medication compliance, include family within the care of their loved ones and enable NHS Trusts to support a wider range of patients with long term conditions.

Case Study: Diabetes Insulin Management

80-year-old Mr M from Bristol has diabetes and COPD. He regularly takes insulin and his glucose level readings and is keen to manage his condition well to slow the deterioration. Mr M has calls set up every day to remind him to take his insulin.

The calls have ensured he manages his conditions well and he has only been admitted to hospital once in the last two years in relation to his diabetes. The calls also have proved useful when Mr M had fallen in his garage and could not get back up – his relatives were notified and were able to come to his aid.

Telehealth and Self Care in Cornwall

Joe Barr knows all too well the problems of living with a long term health condition. He has no less than six of them, including heart disease, Chronic Obstructive Pulmonary Disease (COPD) and stage three kidney disease.

At just 59, he is now faced with a daily task of monitoring and managing his own health so that he can retain his independence and stay out of hospital. The ex-smoker, from St Keyne, blames his long term habit of smoking around 35 cigarettes a day for the health problems he has today. He relies heavily on support from the NHS, including new state-of-the-art Telehealth monitoring equipment, to manage his symptoms daily.

However, extraordinarily, he is also now very much a leader in helping others to manage their long term conditions effectively and, crucially, to try to prevent others from developing such conditions. He is one of a group of seven patients who initially attended an NHS-run COPD training course in Liskeard in 2006 on self-managing the condition. They realised that they would soon be 'on their own' with their condition(s) in terms of day-to-day living and agreed to form the South East Cornwall Breathers support group.

They have since gone on to launch a similar group in Looe and aim to have network coverage across the whole of Cornwall. The team give up their own time free-of-charge to support others with COPD and other smoking-related illnesses and to educate young people about the health risks they face if they start smoking.

Joe explains: "I am on a lot of medication. I try, with the help of doctors and community nurses, to stay out of hospital by learning about my conditions and monitoring the signs so that if I do have a 'wobble' I can seek medical help quickly to stop a problem escalating. "The Telehealth equipment helps me to do this. By hooking up to the machine and taking various readings, such as my blood pressure, health professionals miles away can review my state of health with me throughout each day and react if they see a problem emerging."

Joe, like many within his self-care groups, is determined to remain independent for as long as possible. He strongly believes that as a society we need to support one another through voluntary groups such as his to enable people to have the courage and ability to take charge of their own health. "We have regular meetings and we all share experiences and problems and find answers among ourselves," he said. "It's brilliant when you get a group of 20-30 people in a hall and one may talk about something that's troubling them and another in the group can relate to it and provide some advice or share their own experience, perhaps relating to a specific drug treatment." An important part of the group's work is educating young people in secondary schools in the hope that future generations will also take control of their own health - and much earlier.



Section Five: The Workforce

The issue facing people with LTCs cannot be addressed and the changes needed cannot happen without the workforce being equipped to deliver. Front line staff, who see thousands of people with LTCs every day need to be supported to deliver more personalised care and to understand the culture change needed to support people to understand their condition and feel more in control. This means changing part of their role from being expert 'fixers' to becoming coaches and enablers.

Effective LTC management depends on more than just providing information to individuals, their carers and families. Effective LTC management enables individuals to become experts about their condition and their care. Through shared decision making patients become involved as active partners with professionals in clarifying acceptable diagnosis/treatment/management/support options, discussing goals and priorities, and together planning and implementing a preferred course of action. The principle of shared decision making is integral to the personalised care planning process.

Local services need to be flexible and reliable in ensuring that every person receives the care he or she needs. From supporting self care to case management of those with complex needs, the approach needs to be coordinated to reduce duplication, maximise resources and improve patient outcomes. The creation of integrated health and social care teams based around a locality (or neighbourhood) to provide joined up and personalised services will go some way to achieving this. These generic teams can pull in specialist services when necessary, but treat a patient holistically, regardless of their condition(s). Each patient should have a key worker within this team who co-ordinates their care and acts as the point of contact.

Questions to consider – for commissioners and providers and workforce planners:

- What are the needs of my local LTC population?
- What methods can I use to better understand those needs?
- Are we using risk stratification techniques to understand need?
- Do we also want to use social marketing techniques to better target communications and interventions to different groups?
- Is information from patients being collected on services they want, i.e. through personalised care planning?
- What skill mix do we need to meet the needs of my local population?
- What are the training needs of the workforce – are there gaps?
- How as providers can we ensure we have staff with the skills to deliver?
- Do we need staff to support those with complex needs or to support behaviour change such as health trainers, practice nurses, AHPs, community matrons/case managers?

- Are we using these tools and techniques not only to understand the LTC population but to plan the workforce to meet those needs?
- How can we ensure that this is built in contracts with providers?

The NHS Health & Well-being Review 2009 made clear there is a strong business case for investing in staff health and well-being. Organisations that prioritised staff health and well-being performed better, with improved patient satisfaction, stronger quality scores, better outcomes, higher levels of staff retention and lower rates of sickness absence.

The review states there is compelling and convincing evidence that investing in improving workplace health and wellbeing is not only the right thing to do in itself but it can also bring real and substantial benefits to the NHS and to patients. Healthier staff, teams that are not disrupted by sickness, or where staff are not under undue stress, and lower turnover rates all contribute both to the quality of care given to patients and to patient satisfaction. By contrast, where staff are unhappy and unhealthy, where there are high sickness rates, high turnover and high levels of stress, there are likely to be poorer outcomes and poorer patient experience

Table opposite illustrates this vividly by comparing the outcome measures for 4 non-specialist acute Trusts, 2 of which score highly on staff health and well-being (as measured by injury rates, stress levels, job satisfaction and turnover intentions) and 2 of which score poorly. With few exceptions, the difference in performance is marked and clear.

	Trust A	Trust B	Trust C	Trust D
Absence	4.21%	4.04%	4.58%	4.70%
Turnover	10.50%	9.79%	11.65%	17.02%
Agency spend	1.70%	2.96%	1.71%	4.57%
Patient satisfaction	78.9	76.4	77.4	67.5
MRSA cases per 10,000 bed days	0.65	0.88	1.56	0.95
Standardised patient mortality rate	87.5	100.2	110.0	100.2
Annual Health Check: Quality of services	Excellent	Excellent	Weak	Fair
Annual Health Check: Use of resources	Excellent	Excellent	Weak	Weak

Note: Green figures represent Trusts which are performing well on health and well-being indicators; blue figures represent Trusts which are performing poorly on health and well-being indicators; health and well-being measures in the above table relate to responses in the Annual Staff Survey.

Source: The Work Foundation, RAND Europe and Aston Business School

Workforce Development

A workforce development strategy¹² for people working, supporting and caring in adult social care has been developed by Skills for Care. The strategy is intended to support workforce commissioning, planning and development to meet the new vision and priorities in adult social care. The intent is to put a real focus on supporting personalisation, dignity, independence and choice where as many people as possible are enabled to stay healthy and actively involved in their communities, while those who need support have maximum control over the services they receive.

"Nurses and Allied Professionals have a huge role to play in delivering care and supporting the thousands of people with long term conditions who they come into contact with every day. Being at the frontline of care, they are ideally placed to identify service solutions and drive the culture change that will support people to have confidence to manage their condition".

Karen Middleton, Chief Health Professions Officer

12 <http://www.skillsforcare.org.uk/wds/>

Workforce Development Case Study: Acorn Surgery – Supporting Self Care in Primary Care

In 2008, the Acorn Surgery in Huntingdon took part in a pilot to introduce seven Principles of Self Care (<http://www.skillsforcare.org.uk/selfcare>) into the work of the primary health care team. The aims for the project included a reduction in GP visits and hospital attendances, improved patient satisfaction ratings; more effective partnership and team working and ultimately enhancement in the service the surgery staff provides to their patients.

A baseline survey of patient satisfaction was undertaken at the start of the programme to provide specific feedback on experiences of communication with members of the clinical staff and targets were based on these results.



Action-learning sessions took place and were attended by members of the clinical team. These workshop-based sessions introduced the key concepts of the programme, provided the opportunity to practice skills and allowed for feedback from the multi-disciplinary team. Following the experiences of the clinical team, the administrative and reception teams also received awareness training and skills development in recognition of the vital role they play in patient experience.

The leadership of the practice manager and principle partner and their commitment to the project was key to its success. The project helped increase feelings of solidarity and collaborative working within the practice and resulted in closer links between the surgery team and the patient participation group, drawing on their views and feedback to ensure appropriate issues were addressed at key stages. This enabled the surgery to begin to implement self care principles and focus on new ways of working with and empowering patients in relation to their health and wellbeing.

Worcestershire Acute Hospitals NHS Trust: Self Care Staff Course

Worcestershire Acute Hospitals NHS Trust have developed a self care scheme which has reduced staff sickness absence costs by 55 per cent and improved staff morale for those who attended the scheme course.

Initial evidence suggested that individuals recording high levels of short-term absence were likely to continue to be absent in the future.

Working with Human Resources and line managers, the trust's occupational health (OH) team implemented a '**self care**' course designed by the Working in Partnership Project¹³ to support employees, change behaviour and reduce absence rates rather than managing them through the capability policy.

Working with the Trusts trainers, the 70 staff who participated examined individual perceptions of health and were trained in a model of change, confidence, self esteem and stress management, as well as healthy eating and exercise.

The course offered practical guidance how individual health beliefs might impact behaviour at work, as well as bespoke tools to help improve overall health and well-being.

The course modules included:

- . health and health belief models
- . motivation and making changes
- . self esteem and confidence
- . psychological aspects of health and well-being
- . physical aspects of health and well-being
- . healthy eating and exercise.

Following the **self care** course, attendees' sickness absence costs reduced by an average of 46 per cent in the first 12 months and a further 65 per cent in the second year. This was an annual mean reduction of 55 per cent.

Staff also reported improved team morale and continuity of patient care during the three-monthly review sessions. The participants continue to find benefit from the course and 100% of participants have said they would recommend the course to others.

The **self care** course won the 2009 Excellence in Improving Employee Health and Well-being Award at the national Healthcare People Management Association (HPMA) Excellence in Human Resources Management Awards.

13 <http://www.selfcareconnect.co.uk/wipp-resources> (you will need to register to access course material)

September 2011 update

Worcestershire Acute Hospitals NHS Trust have reviewed the data for the first 8 courses which is now available and the average (mean) annual reduction in sickness absence costs is 47.8% for those who have attended the course. This is calculated from sickness costs for the 12 months prior to people attending the course, compared to their costs 12 months after attending and for 3 courses we have the data for the second 12 months after the course, which importantly has shown an ongoing improvement in attendance.

Data for those who have left the Trust since doing the course has been completely excluded, even if they left during the second 12 month period.

The cost savings as calculated above now amounts to £130, 221.79. This includes only the payable salary to the individual and does not include on-costs or staff replacement costs etc.

Worcestershire Acute Hospitals NHS Trust have been able to facilitate a further 18 NHS Trusts to be able to deliver the Self Care course to their employees.

Section Six: Examples of Local Achievements

Across the country local health communities have been moving forward with innovative approaches to improve LTC care and services. In this section are some examples of the many local achievements that are making a huge difference to the lives of people with LTCs.

Personalised Care Planning in Bradford West Yorkshire

A more proactive, planned approach to LTC management using personalised care planning is being piloted in general practice in Bradford, West Yorkshire and other general practices in the NHS Yorkshire and Humber region. Forty percent of patients in the Bradford practice were identified as having one or more LTCs and twenty five percent had 2 or more LTCs. Those patients have been offered two different clinics for care planning consultations, (i) a 'blue' clinic for those with one to two LTCs who have been offered a 25 minute appointment and (ii) a 'red' clinic for those with 2 or more LTCs who have been offered a 45 minute appointment.



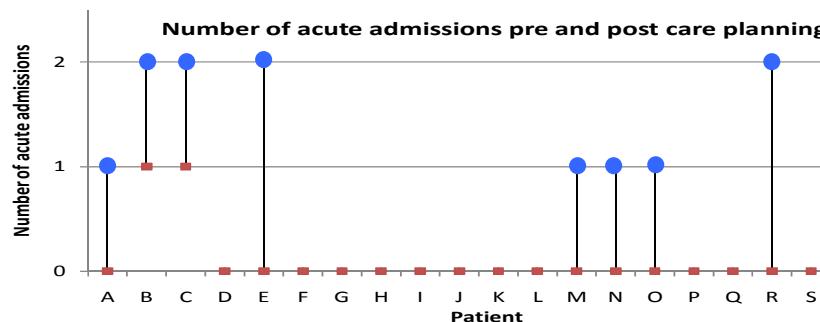
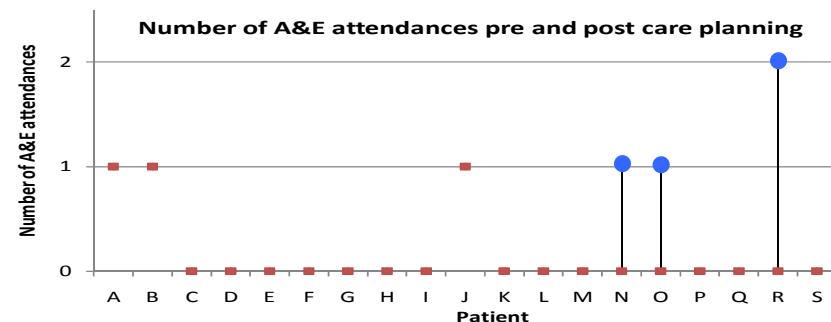
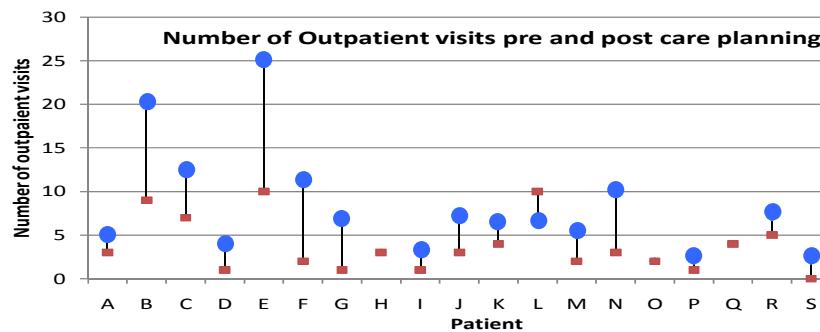
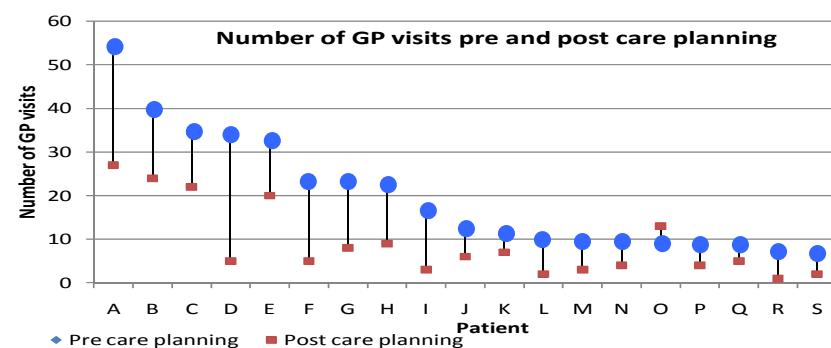
The care planning discussions centre on enabling a true, holistic picture of individuals' concerns, issues, perceptions and requirements. This begins with identifying patients goals using motivational techniques to support specific aims such as weight loss. The care planning discussion, with goals and any actions agreed are recorded in a care planning template which can record different types of goal such as a wellbeing goal or something that aims to reduce complications. Another key feature of the system is recording of services requested that are currently not available, which is valuable information for commissioners. As part of care planning, patients are also offered an information prescription and personalised action plan for self care. The system also links to the Quality and Outcomes Framework (QoF).

Once the care planning process is completed the information is printed off and given to the patient as a record – this is in effect their "care plan" and follow up appointments are made to review progress against goals. Care planning is not viewed as a "one off" event but rather a continuous process of engagement with patients. The care plan is very useful as an aid memoir of the consultation, the goals agreed and potential discussion points for the next care planning session. Patients also have a named individual from the practice such as a nurse leading the care planning consultation, who they can also contact if they need any more information or have concerns or problems relating to care.

Outcomes

Fig 1 below shows the impact on 19 patients one year after care planning on (i) clinical contact with the practice and (ii) the number of outpatient appointments; A&E attendances and acute admissions. Blue circles show before care planning and red squares after care planning.

Patient level impact of care planning



The results show a promising trend in reduced practice contacts after care planning. There also appears to be a reduction in the number of outpatient appointments. The data for A&E attendances and admissions also shows some reductions after care planning although these numbers are smaller.

Self Help Nottingham Supporting Self Care

Within Nottinghamshire, Self Help Nottingham has developed a best practice model of providing robust information about self help/peer support groups to NHS staff and patients. They also provide specialist support and guidance about the most effective ways to nurture a wide range of groups across the health and social care spectrum.

Self Help Nottingham produce an annual directory of self help groups which is made available through NHS intranet services to all PCT staff and paper directories which are available to community based staff. They also operate a telephone and internet information service to the public and professionals which signposts to a range of specialist services for self help/peer support groups including training, publicity and funding advice.

Due to their close relationship with groups, the quality of information made available through the directory services is maintained monthly and offers an accurate tool when signposting patients to groups as opposed to other types of directories, which are only updated annually. This innovative approach to engaging with self help groups ensures accurate information is available to a wide range of stakeholders and has proven benefits to supporting people to self care and improve patient participation in service improvement.

There is growing evidence to show that supporting people to self care through involvement in support groups improves the health and wellbeing of people and can have a significant impact on the use of services. Key benefits to patients include:

- Better symptom management, such as reduction in pain, anxiety, depression and tiredness
- Access to relevant information
- Feeling empowered to take an active role in one's own health
- Increased self confidence and self-esteem
- Opportunities to give as well as receive help
- Learning new practical ways of managing problems
- Gaining inspiration and support from others' experiences
- Feeling more in control and less isolated and alone
- Opportunities to increase social circle
- Opportunities to develop new skills

Cont.....

The project is in its second year of development and is already highlighting the need for health and social care professionals to have up to date reliable information about local self help groups. It is the aim of the project that staff become better equipped to support the development of self care with patients, signposting them to peer support activities with a better understanding of their role in the life cycle of self help/peer support groups. By promoting support groups as a part of self care staff enable improved outcomes for patients and increased job satisfaction.

Peer support groups provide a cost effective way of supporting people to self care and manage their long term condition and replace the use of professional staff to run and manage support groups and networks as groups themselves are empowered to help themselves. This unique service in Nottinghamshire has recently started work to extend their support services to groups across the East Midlands and are keen to support self help initiatives across the UK.

Self Help Nottingham are currently developing a Self help Toolkit to help other areas recreate what has been achieved in Nottinghamshire - high quality searchable information about self help groups which can be made available to professionals and the public.

The Expert Patients Programme

Sue Rogers was diagnosed with diabetes in December 1999. Initially she was prescribed tablets but a blood test revealed she needed to take insulin which she began taking in February 2002

Sue attended a course run by the Expert Patients Programme Community Interest Company (EPP CIC) at the Royal Lancaster Infirmary in January 2011. Sue found the course very helpful and one of the things she learnt is that if you do not understand something, ask rather than going off and then worrying about it.

Before the course, Sue was guessing her insulin dosage. It was only because of the EPP CIC course that Sue worked out the ratio of insulin to carbohydrates she needed. The course was also a great way of socialising and getting tips and advice from others, which was all part of the learning process.

Sue now feels confident going abroad "*I've been to West Africa, Peru and the Amazon. Before the course, I would not have dreamt of doing this. I now feel that I have my diabetes under control*".

Sue participates in a local Active Health Walking Scheme and goes walking every week, and once a month does a one and a half hour walk. She also goes to the sports centre each week where she does a circuit class to help reduce her blood sugar levels and to socialise.

Following the course, Sue has reduced her insulin by a third and has lost weight. She no longer needs to see her GP on a regular basis about her diabetes and instead visits a specialist diabetes nurse two or three times a year.



The Expert Patient Programme Social Return on Investment study¹⁴ provides important evidence that targeted self management programmes can have positive results across wider society. As well as savings for the health sector in the ratio of £3.00 for every £1.00 invested there is a wider social return in the ratio of up to £6.00 for every £1.00 invested, depending on the type of programme.

¹⁴ <http://www.exPERTpatients.co.uk/sroi-report>

Cost Savings through Patient-centredness: The National Refractory Angina Centre, Liverpool.

The Secretary of State's ambition that patient involvement in health decisions should be the norm, is summarised by the phrase; "No decision about me, without me". In practice, time pressures can result in traditional clinics only being able to provide education in a piecemeal, often haphazard fashion. Consequently, audit reveals that misunderstandings about angina and its treatments are common among angina sufferers. The key to NRAC's success is a structured approach to patient and carer education so they are able to become genuine partners in healthcare.

The National Refractory Angina Centre (NRAC) was established in 1996 to harmonise and improve the management of end stage angina. It currently provides the UK's most advanced patient-centred service for people with stable angina.

NRAC pioneered the concept of total user engagement in which patients and carers are continuously involved in the design and development of the service. By involving users in all aspects of the service from defining objectives to fine tuning strategy and focussing exclusively on patient-related outcome measures, it enabled NRAC to evolve a genuinely patient-centred service that "delights" patients, and produces substantial savings as a by product. Research shows that patients who attend patient-centred angina services have a better quality of life, feel less anxious, experience less pain, have fewer emergency admissions and cost less. In simple terms patients whose doctors take the time to listen and explain do better and cost less than poorly informed patients.

The NRAC patient-centred approach has been successfully replicated by practice based commissioning teams in Chesterfield and Wirral. Service quality consistently exceeded patients' and professionals' expectations. Importantly, patient-centred angina services also deliver net savings by enabling patients to avoid unnecessary invasive procedures and emergency admissions.

It is estimated that a GP commissioning consortia covering population of 100,000 could easily enrol one hundred suitable patients annually and realise net savings of between £250,000 and £500,000.

NRAC has routinely collected user satisfaction measures since 2003 and the average satisfaction in 2009 was over 99%. In 2009 NRAC was ranked top among UK businesses for delivering consistently excellent patient experiences.

What patients say about patient-centred angina care.

"The whole experience, I found not only of great benefit but also educational. The fear factor about angina has greatly diminished. I feel I am now back in control of my life"

"In my time dealing with various doctors.... this was the first time that I was actually treated as an equal partner"

Case Management in Oxfordshire

NHS Oxfordshire has taken a systematic approach to improved management of people with long term conditions who have the most complex needs. A thousand patients were identified using the Patients at Risk of Re-hospitalisation (PARR) tool and the Combined Predictive Model as being at risk of frequent emergency admissions. These patients were offered proactive case management, which included jointly agreeing a personalised care plan with their case manager. This included:

- what they could do for themselves with support from their case manager and other professionals to prevent deterioration;
- how they could detect the early stages of deterioration – and action they would take
- what else they could do for themselves with support from their case manager and other professionals to avoid an emergency admission;
- using the “message in a bottle” so that the personalised care plan could always easily be located, especially in an emergency;
- individuals understanding what case management involves, how it can better support them and remembering to always tell hospital staff that they are receiving it if admitted by giving them a yellow card and key ring with the case managers contact details

Benefits from the analysis showed that Oxfordshire:

- patients being case managed had a reduction in admissions and A&E attendance of approximately 40% in the 6 months following starting case management compared to the 6 months before.
- 52% of people reported having an increased Quality of Life after the first six months
- 93% reported they were satisfied with the case management service they received
- estimated savings after the cost of providing the service were in the region of £1m

The analysis showed that performance varied across the county, which could be attributed to the variability in providers of the service or other reasons such as some areas having much lower admissions in the first place so the potential for reductions was less.

NHS Oxfordshire is using the learning from this analysis and in the future is looking into:

- increasing the focus on higher risk people to increase the benefits;
- increasing, smarter workforce skill mix, for example using support workers to monitor and reinforce self management plans;
- increased use of telephone contact to supplement visits and release resource
- potential use of telehealth where viable and appropriate;
- more emphasis on actively working more closely with acute and community hospitals to reduce length of stay;
- a standardised personal care planning process and care plan across the county;
- explore integrated community locality teams using risk stratification to prioritise resource allocation.

Wandsworth Virtual Ward

NHS Wandsworth decided to adopt the Virtual Ward approach to improve patient care and reduce hospital admissions. This began by identifying patients who were most at risk of unscheduled and avoidable hospital admission and then proactively managing them more effectively in the community. **The Community Virtual Ward** reproduces the strengths of a hospital ward in the community by using a multi-disciplinary team approach in healthcare provision. It is called "virtual" because the ward does not exist physically and patients remain in their home.

The core team consists of a GP, Community Matron and Ward Clerk who do daily activity ward rounds and weekly Multi Disciplinary Team meetings, where all the relevant community health professionals are invited along with social services. The attendees generally include District Nurses, Specialist Nurses, Physiotherapists & Occupational Therapists, Social Worker, Intermediate Care Team, Pharmacists and Dietitians. These face-to-face meetings significantly improve the integration and efficacy of services for the patients.

Patients are referred to the Ward using a combination of data from the Patient at Risk of Re-hospitalisation (PARR) tool together with Community Matrons' and GPs' joint case loads. This combination of data provides a more accurate assessment of which individuals are most at risk of unscheduled admission in the next 12 months and would benefit from admission to the Ward. Those referred are then contacted (with adherence to patient confidentiality rules) and offered the service and a home visit is then arranged. Over 95% of patients contacted wanted to be admitted to the Virtual Ward.

During the initial home visit, the aim of the Virtual Ward is fully explained to the individual and this is supported with a patient information leaflet. Patients stay on the ward until their situation improves, which on average is between 6 -18 months. At the time of discharge, patients will be encouraged to become part of an Expert Patients Programme delivered through NHS Wandsworth so that they are supported to better manage their own condition(s) at home, feeling more confident and in control and having less reliance on NHS services.

THE SUCCESS OF THE VIRTUAL WARD

The Virtual Ward approach has led to:

- A reduction in avoidable hospital admissions. The costs of employing the full-time doctors was estimated to be recouped within 5 months of the Community Virtual Ward starting by admission avoidance alone.
- More effective communication between GPs, secondary care and community services
- Increased support for the health care professionals in the community.

Cont.....

- Improved health outcomes and patient satisfaction with services. Patient satisfaction data was collected with 100% satisfaction rates recorded among all patients admitted to the Virtual Ward. Further research is ongoing but preliminary data shows very promising improvements in patient outcomes – particularly in regards to admissions and A&E attendances.

Dr Ann A Phillips: GP Southfields

'I have found the Virtual Ward to be of great benefit to our patients with complex needs and vulnerable to readmission to hospital. This is my considered opinion and I know that other colleagues in our Practice have also appreciated the high standard of care and support that the Virtual Ward has provided. In view of the particular facility offered by the Virtual Ward I would like to support it continuing as an integral part of our Primary Care Team'.

Patient CL's wife:

'very happy with the service provided. It has really made a difference to us, not just in better health but also in sorting out outpatient appointments, booking transport and being able to take blood samples at home'

Sharel Jagroop: Community Matron South Wandsworth

'...it has surpassed my expectations...having a GP on the team has helped me to develop clinically... .I can get timely advice about my patients or get them seen instead of having to chase their GPs who...can be difficult to contact....The administrative support has helped significantly with how efficiently I work and means that I can spend more time with patients. Having the support of both the GP and Ward Clerk has positively impacted on my working life as I do not feel isolated...my role as a community matron involves dealing with very complex health and social care issues which can be very stressful...'.

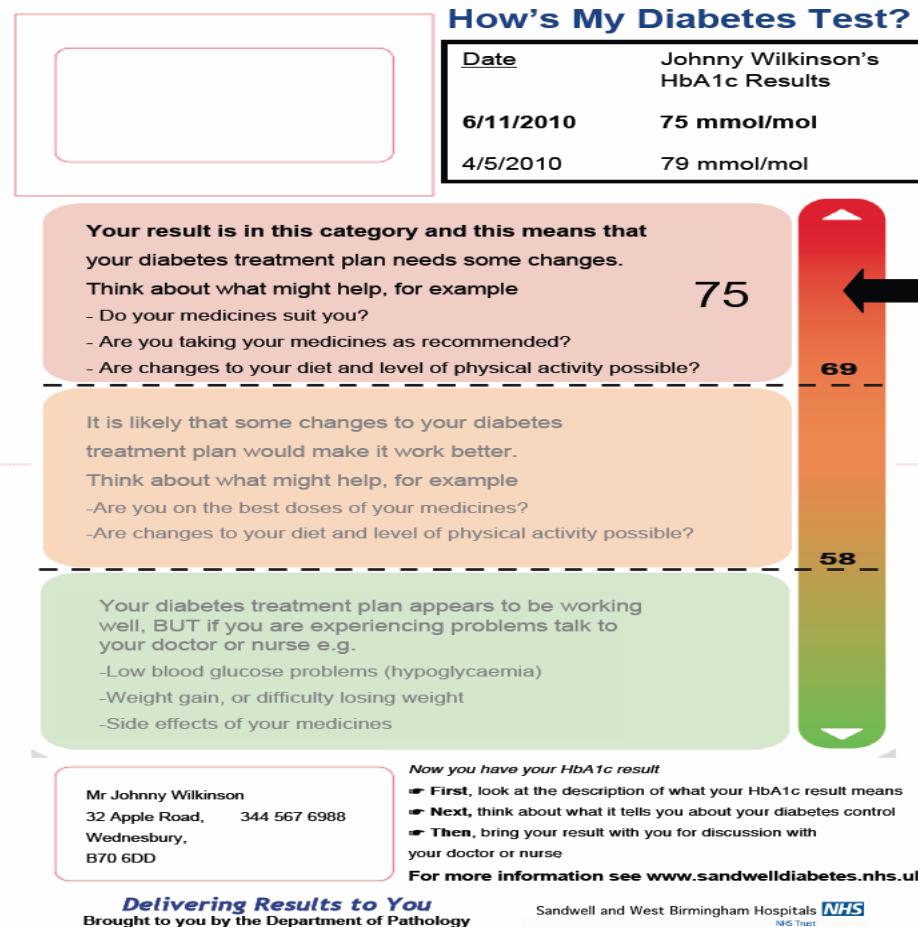
'Empowering Diabetes Patients to have informed discussions with their health care professional through the delivery off HbA1c results directly to patients'

This Sandwell project was a partnership between NHS Sandwell and Sandwell and West Birmingham Hospitals NHS Trust. Patients with diabetes do not routinely receive their blood test results prior to an appointment. This innovative project developed a simple and effective way of delivering HbA1c blood test results directly to patients in order to equip them to more readily self care and be empowered and informed in discussions with their health care professional. The project uses 'mailer' technology linked to the Pathology lab IT system to automate this delivery process in a cheap, lean and simple methodology. Patients receive in the post a colourful, easy-to-understand 'mailer' which informs them of their HbA1c result and enables them to more fully understand what that result means. They can then take

this information with them to their care planning appointment with their health care professional. In a pilot of 1800 test results delivered in this way, a 10% sample evaluated this innovation very well;

- 73% of people stating that getting their HbA1c result before their appointment helped them,
- 76% said having their result made it easier to talk to their doctor/nurse,
- 89% said they wanted to receive results in this way in the future
- 72% of consultations were helped by this project according to HCPs.

This method of delivering HbA1c results to patients only costs 35p per result. The feedback from patients was that it prompted many to consider behavioural changes in their diet, physical activity and medication adherence to improve their self management of diabetes.



A personal mailer is a single sheet of A4 paper, bought pre-printed with the chosen design. Patient identification information and the HbA1c result is then automatically printed onto the mailer, it is automatically heat-sealed and posted the same day. The recipient tears off the perforated edges to reveal the enclosed information. Many pay slips in the NHS use the same mailer technology.

The IT system in the Pathology Lab at SWBH was enabled to automatically print HbA1c results (only for the practices involved in the pilot) onto the pre-printed mailers. These mailers were then fed through a heat sealer machine that closed the mailers ready to be posted by the Pathology Lab.

Personal Health Budgets

Personal health budgets allow people with Long Term Conditions to have more choice, flexibility and control over the health services and care they receive. At the heart of a personal health budget is a care plan. This is sometimes referred to by other names, like a support plan. The plan is developed in partnership with a health care professional, for instance a community nurse, or someone from a voluntary or community organisation, for instance the MS Society. It must be then be signed off by the NHS Primary Care Trust (PCT). The plan sets out people's health care and wellbeing needs, health outcomes, the amount of money in the budget and how this will be spent.

The Department is currently conducting a pilot programme involving around half the primary care trusts in England is currently underway, testing out personal health budgets in the NHS. Twenty of these pilot sites have been selected for an in-depth study as part of a wider evaluation exploring the potential of personal health budgets to benefit different groups of people. The pilot programme will run until 2012.

Case Study

Sylvia, aged 67 from Dorset suffers from the combined effects of Fibromyalgia Syndrome, Osteoarthritis, and Sjogrens, an autoimmune rheumatic disease. Since 1994 Sylvia's disability had taken control of her every day life and she spent most of her days sat watching daytime television, which she found soul destroying.

Sylvia's community matron suggested that she apply for a personal health budget. Ray, from Dorset Primary Care Trust, visited Sylvia at her home and discussed her healthcare needs, particularly what things such as outside interests and help around the home, which would help Sylvia, cope better with her symptoms.

A care plan was completed which set out Sylvia goals and an action plan of her priorities and Sylvia was allocated a personal health budget of 10-12 hours per week of help at her home, plus three hours for a cleaner. This meant she could take up her hobbies art and creative-writing classes, which the personal health budget also pays for. Being able to do activities outside the house, together with the confidence boost that this has given her, means Sylvia is able to cope better with her pain.

The Greenwich Community Health Services Virtual Admissions Avoidance Team

The Admissions Avoidance team was set up in December 2009 in response to a growing and urgent need for community services to step up the effort required to relieve congestion within secondary care.

The primary objective of the team is to work collaboratively with London Ambulance Service and GPs to prevent both avoidable A&E attendances and hospital admissions. The team has met regularly within the last 11 months and have developed a portfolio of clinical pathways and standardised templates that will be used as an alternative to automatic hospital attendance. The pathways include;

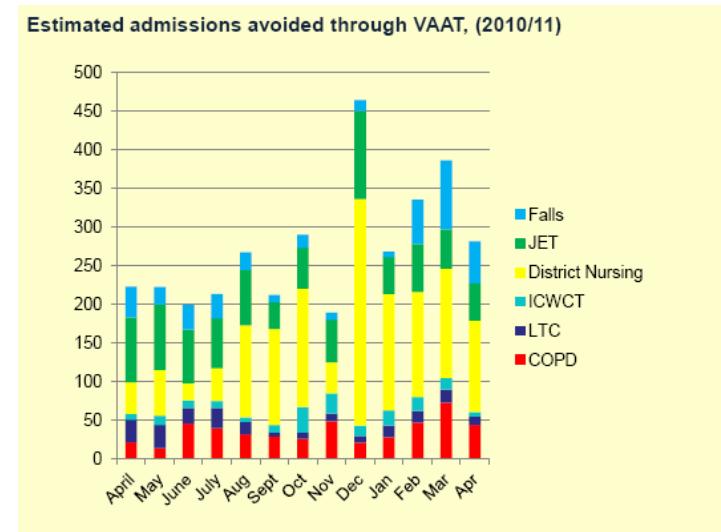
- Cellulitis
- UTI
- LTC; diabetes, Heart Failure, Generic
- COPD – exacerbation, poor self-management
- Falls
- Rapid Response for complex care (MDT assessment) including social crisis
- Blocked catheter
- End of life care

Key elements that ensure the team's continued success are;

- Early identification, rapid assessment and triage within the community
- Early decision making at a senior and expert level
- Close liaison and collaboration with other health and social care colleagues across the health economy to enable the patients to remain at home
- Focus on enabling the patients to self-manage with understanding and confidence
- Regular feedback from service users and their carers

Benefits

- Patients are receiving safe, appropriate, and outcome-focused 'urgent care' in their own homes
- Positive, tripartite partnership between the team, its patients and their carers to enable patients and their carers to understand and manage their conditions safely so that they feel confident to remain at home



Long Term Conditions Compendium of Information: Third Edition

- Supporting patients to die comfortably at home if that is their wish
- Improving the patients' overall experience of the health service at a time when they are clinically vulnerable
- Reduction in avoidable admissions
- Reduction in avoidable A&E attendances
- More collaborative working with local partners
- The estimated impact of the scheme is **3549** admissions avoided in 10/11, equating to a potential £8.8m savings

Case Study Complex elderly care

Greenwich Community Health Services Virtual Admissions Avoidance Team helped Ben, a 92-year-old housebound man with repeated admissions for UTI, associated confusion and loss of mobility. He also had hypertension, severe arthritis, and was socially isolated.

Jenny, a Community Matron assessed him at home and then contacted his GP who arranged a urology referral and referred Ben to the Admissions Avoidance Team. Ben was found to have chronic retention of urine and a supra-pubic catheter was inserted to alleviate the problem and to reduce number of recurrent infections. Jenny monitored his blood pressure, took his blood and reviewed the results regularly. She also reviewed his medication in conjunction with his GP and ensured that he was compliant with the prescribed regime.

Jenny then asked the Community rehabilitation team to undertake a mobility assessment on Ben. Following the assessment, the team arranged for an improvement in access to the bathroom and his intercom system was also reviewed to enable him to access it effortlessly. Jenny also liaised with social services to arrange a place at a local day place.

Before Jenny's involvement (21 months), Ben had six unplanned admissions in 1 year. Since Jenny's involvement, Ben has only had two admissions, one of which was planned.

Annex A – Supporting tools/publications

Self Care

- ***Help and advice for living life well with a long term condition.*** A patient leaflet which explains support and advice available to people with long term conditions
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_102996
- ***Making the case for self care education.*** A business case tool for commissioning self care education summarising the costs, cost savings and benefits for your organisation
www.selfmanagement.co.uk/self-care-resources
- ***The 'Common Core Principles to Support Self Care – a guide to support implementation'*** aims to help health and social care services give people control over, and responsibility for, their own health and well-being, working in partnership with health and social care professionals
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_084505

Care Planning

- Patient leaflet on personalised care planning which explains to patients with long term conditions what they should expect from personalised care planning and their care plan is now available
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114939

E-Learning

- **Care Planning** - A 90 minutes introduction in 3 modules to personalised care planning – what it is, how it can benefit patients and staff and the skills, approaches and behaviours needed for effective delivery
http://www.nhsemployers.org/PlanningYourWorkforce/educationandtraining/LongTermConditions/personalised_care_planning/Pages/E-learningtoolkit.aspx
- **Self Care** - Three short modules are designed as an introduction to supporting people with long term conditions to self care
www.e-lfh.org.uk/projects/supportingselfcare/index.html

E-Learning

- **End of Life Care** - Aims to enhance the training and education of all those involved in delivering end of life care to people, so that well-informed high quality care can be delivered by confident and competent staff and volunteers, across health and social care
www.e-lfh.org.uk/projects/e-elca/index.html
- **Information Prescriptions** - A 90 minute introduction to Information Prescriptions, and how they support people with LTCs to manage their condition. The 4 modules focus in the skills and competencies needed to assess and respond to individual patients' needs for information through an information prescription
<http://www.nhsemployers.org/PlanningYourWorkforce/educationandtraining/LongTermConditions/InformationPrescriptions/Pages/E-learning-tool-for-staff.aspx>

Risk Prediction Tools:

- The Patients at Risk of Re-hospitalisation (PARR++) software algorithm uses hospital inpatient data and is free for use by NHS organisations to systematically identify patients who are at risk of repeated admission to hospital.
- The Combined Predictive model uses both hospital and community data to predict not only those at risk of repeated re-admission, but also those at risk who have never had an admission. The model stratifies risk across the whole population, allowing more timely and appropriate interventions.
- PARR++ and the Combined Predictive Model is available at www.dh.gov.uk/en/Healthcare/Longtermconditions/index.htm

Delivering Care for Long Term Conditions Information Sheets

Eight Information sheets aimed at the NHS workforce and health and social care professionals, which cover a range of topics and are available to download at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121603

- Information sheet 1: Personalised care planning
- Information sheet 2: Care plan diagram
- Information sheet 3: Care coordination
- Information sheet 4: Managing need and assessment of risk
- Information sheet 5: How information supports personalised care planning and support for self care
- Information sheet 6 What motivates people to self care
- Information sheet 7: Goal setting and action planning as part of personalised care planning
- Information sheet 8: End of Life Care and personalised care planning

QIPP: (you will need to register on NHS Networks to access the QIPP information below)

- **NHS Networks QIPP LTC Ignition Phase Network**
www.networks.nhs.uk/nhs-networks/qipp-ltc-ignition-phase-network
- **Commissioning examples**
<http://www.networks.nhs.uk/nhs-networks/qipp-ltc-ignition-phase-network/resources-1/LTC%20QIPP%20COMMISSIONING%20TOOLKIT.doc/view>
- **Virtual WebEx Programme**
www.networks.nhs.uk/nhs-networks/qipp-ltc-ignition-phase-network/webex
- **Care to Share**
www.networks.nhs.uk/nhs-networks/qipp-ltc-ignition-phase-network/care-to-share
- **Commissioning Toolkit –**
<http://www.networks.nhs.uk/nhs-networks/commissioning-for-long-term-conditions/resources-1/lcc-commissioning-pathway/introduction-to-the-long-term-conditions-commissioning-pathway>

Other supporting tools:

- **Well-being Star** – An outcome based tool for supporting and measuring change when working with vulnerable people. The tool can be adapted for people with long term conditions.
www.outcomesstar.org.uk/
- **Healthy Foundations Life Stage Segmentation Model** – uses an evidence based approach to understanding some of the population differences that influence behaviour and impact on health with a particular focus on health inequalities. This can help identify early, tailored and cost effective interventions and ultimately support people to make positive behaviour change.
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_090348

Commissioning

- *Improving the health and well-being of people with LTC* in January 2010. The main aim of the information tool is to share a common vision of what a good service for people with LTC, and to provide some practical suggestions for commissioners to help them achieve that vision.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111122

Workforce

- **Workforce Development Strategy.** This is intended to support workforce commissioning, planning and development to meet the new vision and priorities in adult social care.
<http://www.skillsforcare.org.uk/wds/>

Long Term Conditions Programme
www.dh.gov.uk/longtermconditions