

A large, teal-colored graphic element that starts as a thin line on the left, curves upwards to a peak, and then curves downwards to the right, ending as a thick wedge. It spans across the middle of the page.

*Chronic disease management:*

**A compendium of information**

**May 2004**



# *Chronic disease management:*

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*“Health care systems world wide are faced with the challenge of responding to the needs of people with chronic medical conditions such as diabetes, heart failure and mental illness”*

(World Health Organization, 2002)

# Introduction

## Who should read this compendium?

In this compendium we have brought together much of the evidence about chronic disease from the UK and around the world. We hope it will support people who provide care for those who suffer from chronic diseases, and inform those that commission and manage the services that provide care for people with chronic diseases.

In particular, we think there are important messages for the commissioners of care, Primary Care Trusts, and we would encourage PCT Directors and Boards to read this compendium. Further, those who provide care (general practices, community care, hospitals and social care) can all learn how to build on their strengths.

## Overview

The evidence we have brought together shows that

- Chronic disease is an important health issue, and is growing in importance
- Your social circumstances affect the chance of you having a chronic disease greatly
- Some patients have multiple chronic diseases, which make their care particularly complex
- A small number of patients and diseases account for a disproportionate amount of health care use (especially hospital care)
- There is evidence that chronic disease can be better managed through
  - Increased support for self care
  - Strengthening usual primary care
  - Offering responsive specialist care
  - Managing vulnerable cases by anticipating their needs
- This approach is enshrined in the Chronic Care Model, the adoption of which has clear implications for the NHS
- The benefits from chronic disease are two fold; better outcomes for patients and benefits for the NHS.

# Why is chronic disease management important?

That chronic disease is the biggest problem facing health care systems world wide seems unarguable

60% of adults in England report a chronic health problem



The UK has a total population of 59 million; common chronic diseases include:

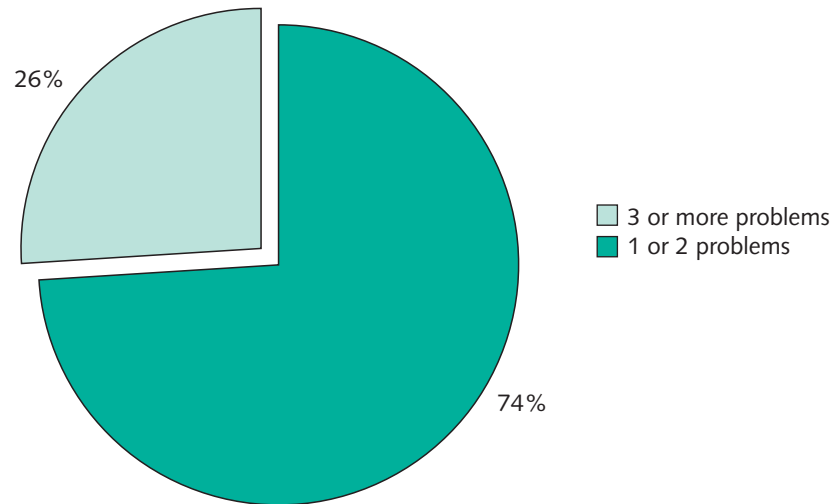
- **Diabetes Mellitus** current estimates put the number of diabetics at 1.3m people with perhaps another million undiagnosed.
- **COPD** affecting 600,000 people
- **Asthma** affecting 3.7m adults and 1.5m children
- **Arthritis** affecting about 8.5m in UK
- **Epilepsy** with 400,000 sufferers England & Wales (1998)
- **Mental Ill Health** affecting 1 in 6 of the population, including 1 in 10 children
- 8.8m people in England have long term illness that **severely limits their day to day ability to cope.**

**Chronic diseases are diseases which current medical interventions can only control not cure.**

**The life of a person with a chronic condition is forever altered – there is no return to “normal”**

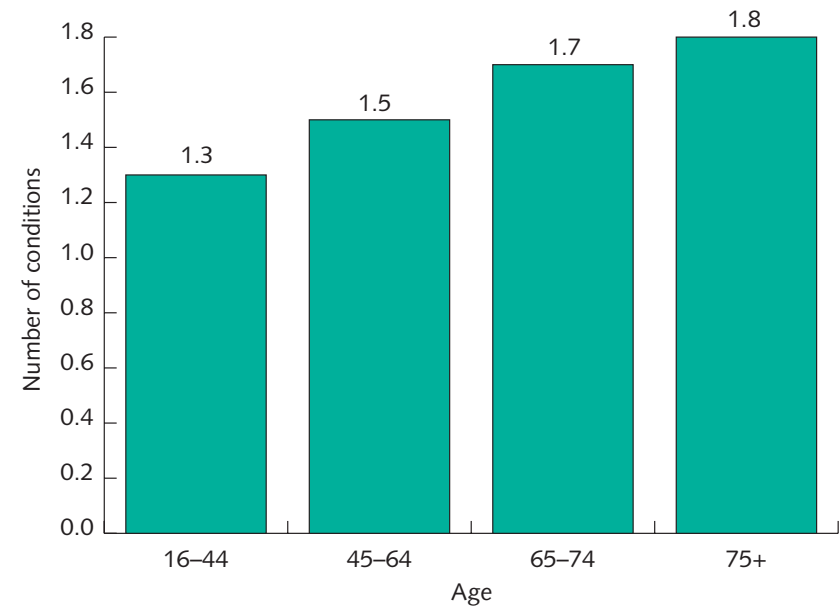
US data suggests that 45% of those with chronic disease are likely to have more than one chronic condition, for those over 65, this rises to nearly 70%. In the UK around a quarter of those people with a long standing problem have **3 or more problems**, making care far more complex.

Proportion of people with a chronic disease with 3 or more problems



(Source: British Household Panel Survey 2001)

Average number of chronic conditions (for those with a chronic condition)

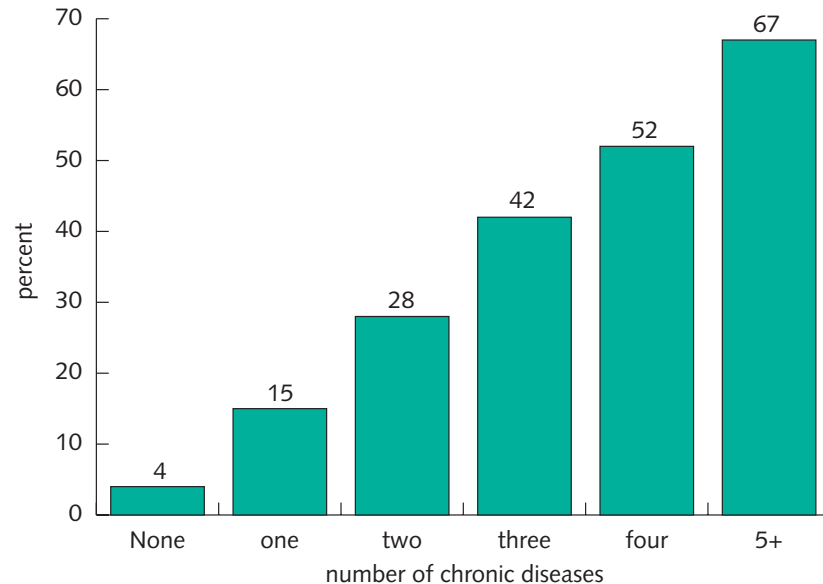


In some cases, having more than one condition is the norm  
(Source: General Household Survey 2002)



Chronic *disease* is probably the wrong term, as most people with longstanding medical conditions also have other complex needs leading to other disabilities often requiring care from other sources, especially social care. The more diseases you have the more likely you are to have difficulties with usual daily activities.

### % of people with activity limitations



Phil has heart failure and so is on a complex mix of medicines and has atrial fibrillation, and so is also on warfarin and depression, and diabetes, and cares for his demented wife, and is already on simple analgesics, including codeine which has made him constipated and has increased pain in his knee meaning increasingly he cannot cope with his duties as a carer...

The problem for people with multiple complex problems is that they:

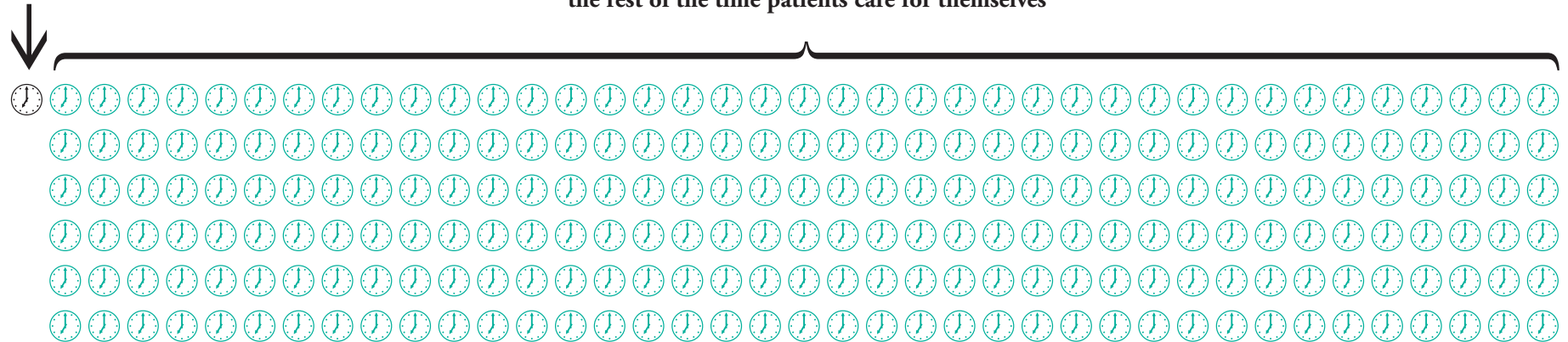
- often have a mix of medical conditions that lead to complex medicine regimes. If they are under the care of specialists they require many visits to hospital (although in the UK much of that care is provided by their general practice)
- often have many social needs
- may be isolated from their family (or their family cannot help as they work full time)
- find the non life threatening problems cause the greatest difficulty (e.g. arthritis is a major priority for the elderly but the drugs to treat it cause many side effects)
- have co-morbidities that can be missed, most notably depression<sup>ii</sup>

The example on the right is a real case (but the name has been changed), and is by no means unusual.

Whilst the support of health and social care is important to people with chronic disease and their carers, they have to live with their condition for 24 hours a day, 365 days a year.

**Health care professionals may only interact with people with a chronic disease for a few hours a year...**

**the rest of the time patients care for themselves**



What does having a chronic disease mean to patients?

"I don't always look after myself all the time ... The truth is I am scared about the long term, I'm scared of going blind or having my legs chopped off. But you have to focus and manage those risks like any other. Self management is the cornerstone of diabetes care, however, you don't need to be an 'expert patient' to take control of your own diabetes. You need a relationship with the right professionals to help you understand all the issues, make the right decisions, and achieve the right balance."

Interview with Stuart Bootle, a GP who has had diabetes for 20 years BMJ 2003;326:1325

"There are few people in the world that haven't been sick at some time in their life. Fortunately, on most occasions, these unpleasant periods are of short duration and it isn't long before one is back into life's routines. During the 'sick period', a person is cared for by loved ones, visited by friends, and encouraged to get well quickly. Generally, the person looks sick and has a disorder known to most people. They even have a rough idea of when they will be well again. Though unpleasant, this kind of 'being sick' is bearable to both the individual and those around them, particularly in view of the fact that an end to their illness is in sight."

For those who suffer from a chronic disorder and particularly one relatively unknown to the general public, but obvious to them, being ill is a different situation altogether. A painful disorder that drags on and on, tests the mettle of the sufferer and the patience and tolerance of those around."

From Scleroderma Lupus Association

<http://www.haps.nsw.gov.au/patrsrscs/patsclero/chrncdis.htm>

Therefore, we need to ask,

## What kind of health and social care system is it that can support people with enduring medical and social problems?

In the remainder of this chart book we look at

- 1) How the NHS is currently configured and the problems this creates
- 2) Who currently has enduring medical and social problems and how they use the NHS
- 3) What evidence there is about managing enduring medical and social problems more effectively
- 4) How we might better support people with enduring medical and social problems, with messages for the NHS and social care
- 5) What are the likely benefits of better chronic disease management?

# How is the NHS currently configured and what problems does this create?

Some argue that health care systems around the world are heavily weighted towards acute, episodic care. As one expert on chronic care puts it:

*“The predominant acute disease paradigm is an anachronism. It is shaped on a 19th century notion of illness as a disruption of the normal state produced by a foreign presence or external trauma, e.g. infection or injury. .... Under this model acute care is that which directly addresses the threat. .... In fact, modern epidemiology shows that the prevalent health problems of today (defined both in terms of cost and health impact) revolve around chronic illness.”*

Bob Kane<sup>iii</sup>

But, there are quality concerns about chronic care in general practice<sup>iv</sup>, variable, often poor, co-ordination of care between community and hospitals, and frequently little integration between health and social care.

The differences between acute disease and chronic conditions can be summarised in this table<sup>v</sup>

	Acute disease	Chronic illness
<b>Onset</b>	Abrupt	Generally gradual and often insidious
<b>Duration</b>	Limited	Lengthy and indefinite
<b>Cause</b>	Usually single	Usually multiple and changes over time
<b>Diagnosis and prognosis</b>	Usually accurate	Often uncertain
<b>Technological intervention</b>	Usually effective	Often indecisive; adverse effects common
<b>Outcome</b>	Cure possible	No cure
<b>Uncertainty</b>	Minimal	Pervasive
<b>Knowledge</b>	Professionals knowledgeable, patients inexperienced	Professionals and patients have complementary knowledge and experiences

Poor management of chronic diseases leads to wasteful use of high intensity resources.

80% of bed days in hospitals are currently used by emergency beds



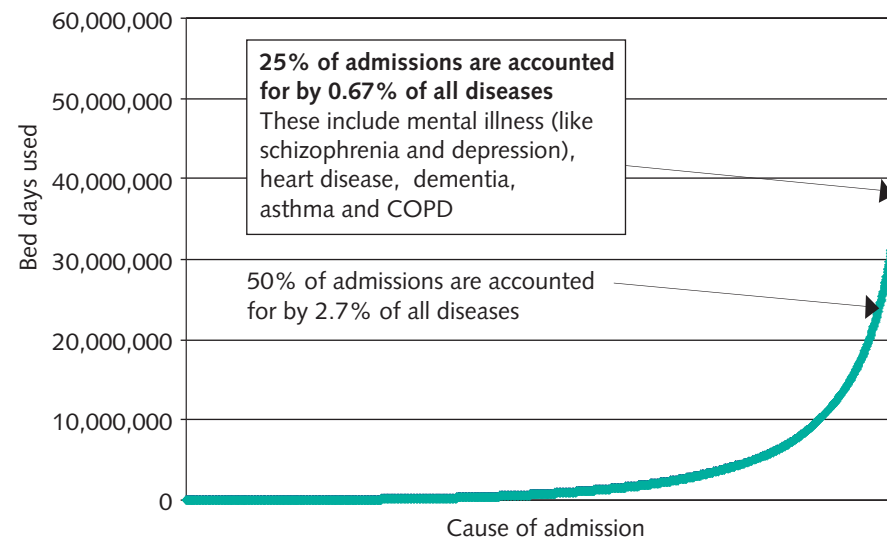
Many of these admissions are preventable; by strengthening care in the community and general practice many patients may never need hospital.

Of the eleven leading causes of hospital bed use in the UK, eight are due to conditions which if we strengthened community care could lead to a fall in admissions



50% of bed day use is accounted for by only 2.7% of all medical conditions, **most of which are chronic diseases**. (Source: HES data 2002)

Cumulative bed day use by ICD code



There is evidence that the routine day to day care of chronic diseases is not good enough.<sup>vi</sup> For instance, in one study only 49% of patients with diabetes had had the back of their eyes examined routinely for retinal damage and only 47% of eligible patients had been prescribed beta blockers after a heart attack.<sup>vii</sup>

By failing to manage chronic diseases effectively on a day to day basis, patients are developing unnecessary complications and dying prematurely. A system that means that an emergency admission is the only source of help when things are going wrong means unnecessary exposure to harm; a hospital admission for a frail older person is often disabling and sometimes fatal. Patients in this cycle of care often feel vulnerable and helpless. This does not have to be the case.

In health systems that have reconfigured themselves to manage chronic disease systematically there have been dramatic changes.



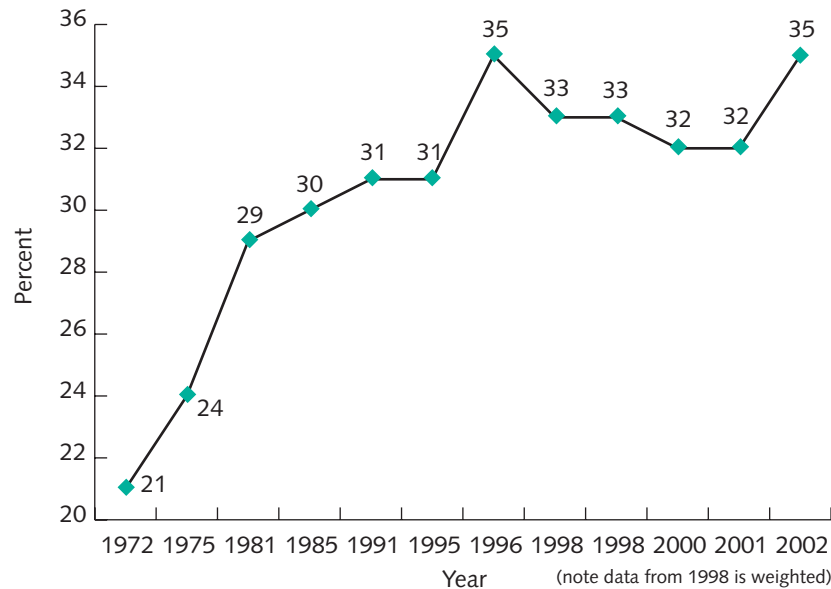
#### Three lessons from abroad

- Veterans Health Administration, USA: The transformation of the Veterans Administration is notable in that from 1994 through 1998, VA bed-day use fell by 50 percent, rates of medical-clinic visits and visits for testing and consultation increased moderately, and rates of urgent care visits fell by 35 percent. However, at the same time, and perhaps contributing to the fall in bed days, was a dramatic improvement in care. It seems probable that some of this shift was the focussed attention on chronic diseases, which showed the most dramatic improvements in care<sup>viii, ix</sup>.
- Kaiser Permanente, California: The dramatic differences in bed day use between Kaiser, the NHS, and other health providers in the US is ascribed to a number of factors, but at least in part to their management of chronic disease, facilitated by greater integration between generalist and specialist.<sup>x</sup>
- Canada: There has been a 7% fall in unplanned and emergency hospitalisations from 1998 to 2002, particularly in patients with asthma and mental health problems. The reasons for this marked decline is attributed to a number of interventions focussed on better management of chronic disease including; report cards; knowledge management; guidelines and protocols for patients and physicians; and learning from top performing physicians.<sup>xi</sup>

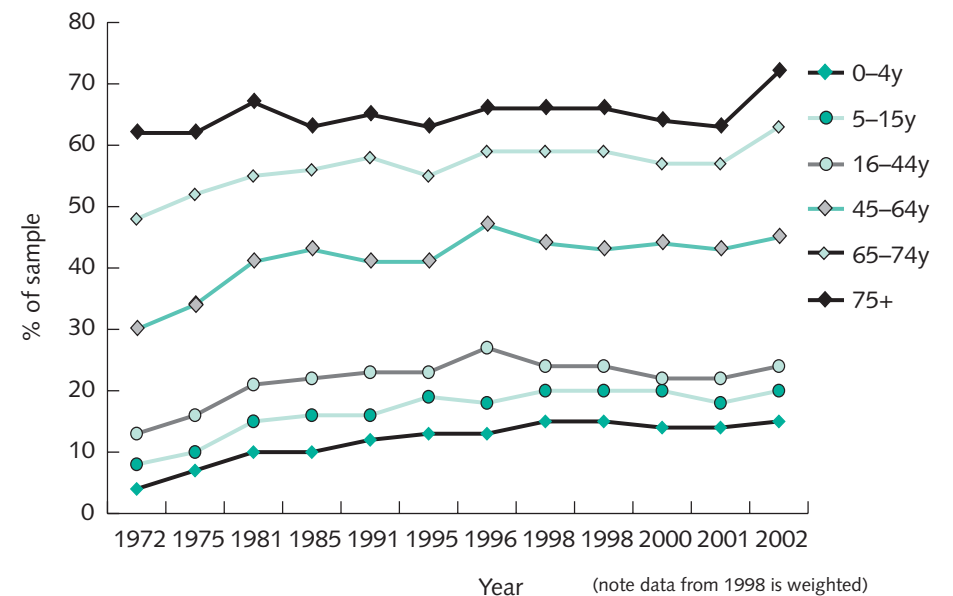
# Who are the people with enduring medical and social problems and how do they use the NHS

The number of people with chronic conditions is rising in the UK (Source: General Household Survey 2002)

All people reporting a chronic condition



People reporting a chronic condition (by age)



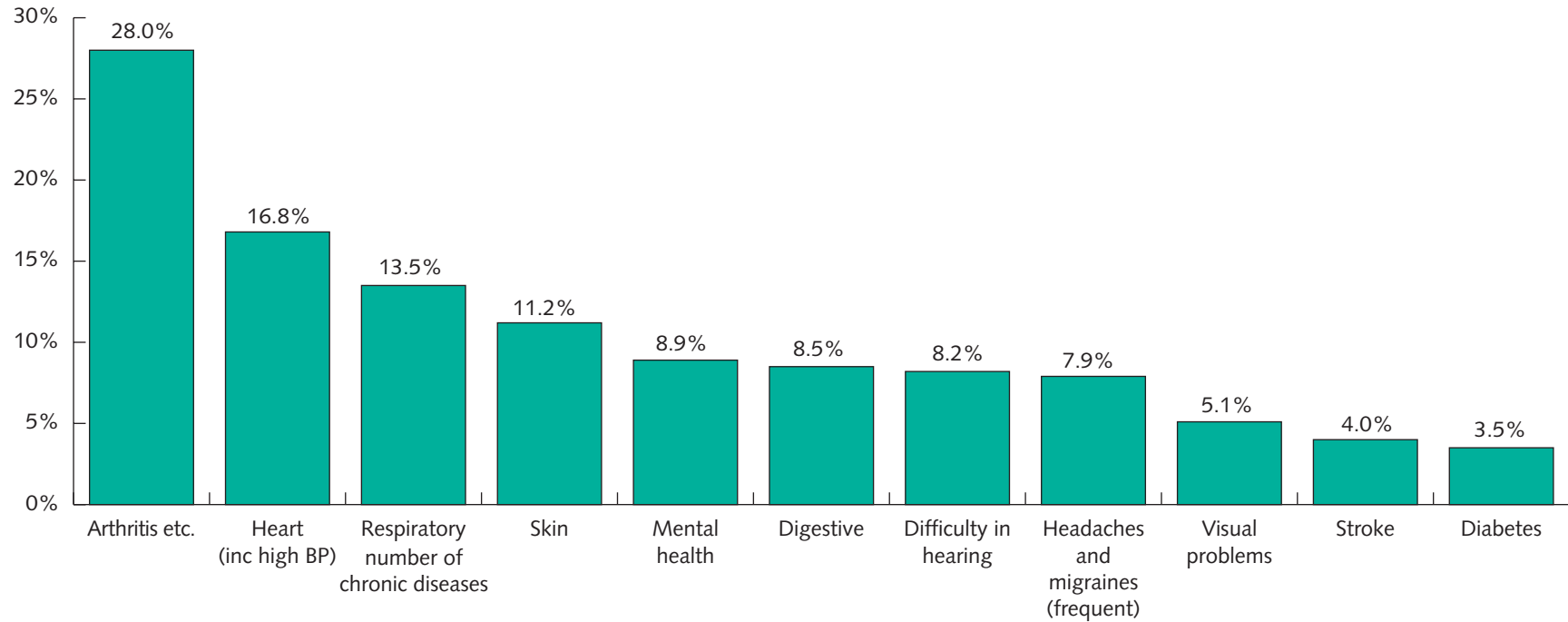
Children also have chronic diseases; in the UK, 15% of the under fives, and 20% of the 5-15 age group (Source; General Household Survey 2002).

Your likelihood of reporting a chronic problem is increased slightly if you are a woman, but increased greatly depending on your socio-economic circumstances (source; General Household Survey 2002).





The commonest chronic diseases are arthritis and rheumatism, and heart problems (including high blood pressure).



(Source: British Household Panel Survey 2001)

Problem (reported as not being temporary)	Percentage of sample responding		
	Up to 64	Overall	65+
None	45%	<b>39%</b>	13%
<b>High prevalence...</b>			
Problems or disability connected with: arms, legs, hands, feet back, or neck (including arthritis and rheumatism)	22%	<b>28%</b>	55%
Heart/ high blood pressure or blood circulation problems	10%	<b>17%</b>	44%
<b>Middling prevalence...</b>			
Chest/ breathing problems, asthma, bronchitis	12%	<b>14%</b>	20%
Skin conditions/allergies	10%	<b>11%</b>	12%
Anxiety, depression or bad nerves, psychiatric problems	9%	<b>9%</b>	8%
Stomach/liver/kidneys or digestive problems	8%	<b>9%</b>	13%
Difficulty in hearing	5%	<b>8%</b>	24%
Migraine or frequent headaches	9%	<b>8%</b>	5%
<b>Low prevalence...</b>			
Difficulty in seeing (other than needing glasses to read)	3%	<b>5%</b>	14%
Stroke	4%	<b>4%</b>	5%
Diabetes	2%	<b>4%</b>	9%
Other health problems	1%	<b>2%</b>	4%
Cancer	1%	<b>1%</b>	5%
Epilepsy	1%	<b>1%</b>	1%
Alcohol or drug related problems	1%	<b>1%</b>	0%

(Source: British Household Panel Survey 2002)

Having a chronic disease means you are far more likely to need health and social care;

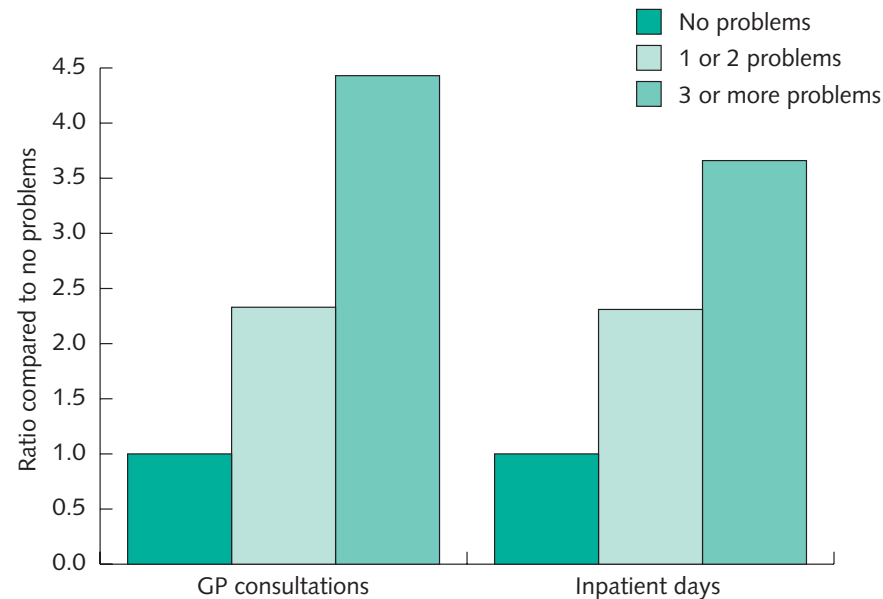
- Patients with a chronic disease account for 80% of all GP consultations
- They are twice as likely to be admitted to hospital
- And stay in hospital disproportionately longer

And this use of health services rises exponentially for people with more than one longstanding problem

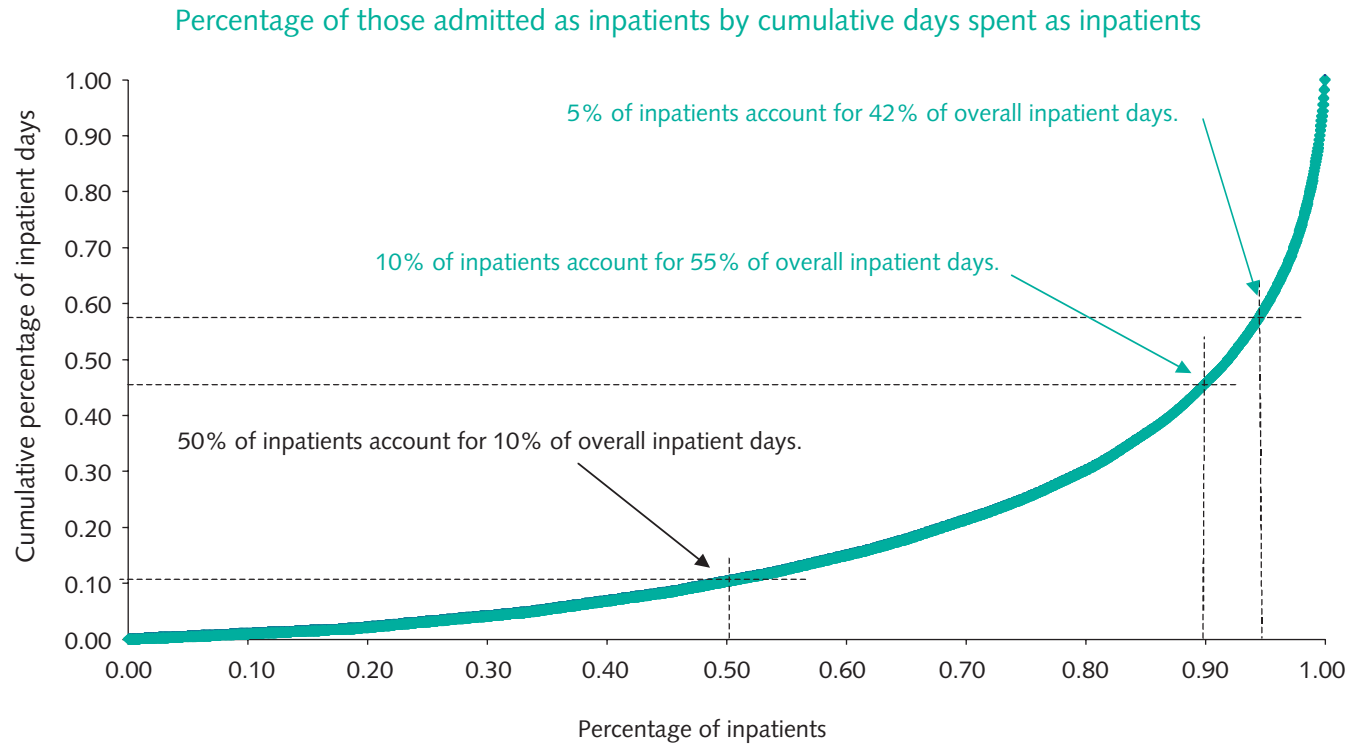
(Source: British Household Panel Survey 2002)

Number of problems	Percentage of sample	Percentage of all GP consultations	Mean inpatient days	Proportion of inpatient days
No problems	38.7%	18.3%	3.99	19.5%
1 or 2 problems	44.6%	49.1%	10.52	51.9%
3 or more problems	15.5%	32.5%	16.79	28.6%

Increased likelihood of needing to use health services with increasing no's of chronic problems



This means that some patients, generally those with multiple complex chronic problems, use health care disproportionately, often leading to unnecessary hospital admissions. Furthermore, this group represents a small proportion of the population as a whole.

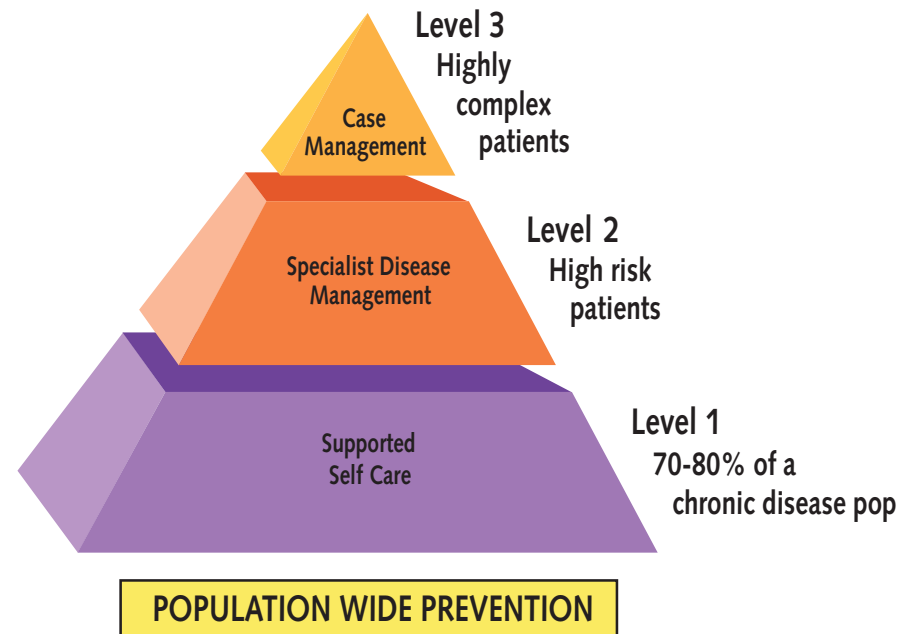


(Source: Analysis of British Household Panel Survey)

Being under 65 means that the disproportionate effects of having multiple longstanding problems is greater than if you are over 65 (Source: British Household Panel Survey 2002).

As we will see, there is much that can be done to better manage chronic disease in general, better support those with chronic diseases that lead to frequent unplanned hospital admissions, and help those with multiple complex chronic problems that are in hospital far more than is necessary.

# What evidence there is about managing enduring medical and social problems more effectively



## Pyramid of care

This pyramid, adapted from Kaiser Permanente, demonstrates the different patient groups that need help. We shall go through each of these, outlining the research evidence and what might be done to improve care for each group. In this compendium we focus on:

- Supported self care
- Specialist disease management and,
- Case Management

## Self care

Although sometimes ignored, or a low priority for health care providers, self care is a well proven and highly effective means of improving the care of chronic diseases.

A review by the Department of Health's Economic and Operational Research division reviewed the effects of self care and robust research evidence of generic self care interventions. For instance, in studies to improve self care:

- visits to GPs can reduce by over 40% for high risk groups<sup>xii</sup>
- hospital admissions reduce by 50% in a Parkinson's disease<sup>xiii</sup>
- outpatient visits reduce by 17% generally<sup>xiv</sup>
- hospital length of stay reduce for mental health problems<sup>xv</sup>
- medication intake more appropriate, e.g. steroids reduced in the treatment of asthma<sup>xvi</sup>
- A&E visits reduce significantly for patients with asthma<sup>xvii</sup>
- days off work can reduce by as much as 50% for people with arthritis<sup>xviii</sup>

It is clear that self management is not simply a matter of providing information to patients, it is a range of different things:

But those that work the best are:

- Patient and carer education about self management of their illness, helping them to understand what to do, how to adjust their medication dose, and how and when to use health care.
- Prompts and reminders for when they should be doing something and attending for care.
- Support from a knowledgeable patient (often, but not always an expert in their disease) and broader networks, including attending practices as part of a group of patients with the same condition

What does this mean for patients?

Types of self care support (with examples)			
SUPPORT CARE	Information and knowledge	Training and networking	Facilities and equipment
Prevention/promotion	Interactive online courses, information on health TV	Lifestyle courses Personal Trainers	Gyms Personal Portals
Diagnosis	Home healthcare literature	Training in self-diagnosis	Home pregnancy test Blood and Urine tests
Decision on action to take	Telephone helpline Interactive video on treatment decisions	Decision support Patient peer groups Internet discussion groups	Personal Portals Decision Algorithms
Treatment/medication	First aid manuals,- software tools for mental health self-help	First aid courses, self care courses	First aid kit: OTC medication, home dialysis, public access defibrillators
Maintenance and rehabilitation	Self-management in post hospital care	Self care community groups	Mobility and household aids
Monitoring and evaluation	Self-maintained medical records	Supermarket MOTs	Home or public access BP monitors Blood glucose testing

Some quotes from the expert patient programme:



The future of self care is unclear, except that it is likely to increase in importance because of

- The rise in information available to patients,
- the ability of IT to support self care,
- the availability of reliable and accurate home monitoring systems,
- the greater desire of some patients to be the locus of control

It is not inconceivable for some patients that they will be the sole care givers with only occasional input from health services to provide any necessary medications.<sup>xix</sup>

## Supporting care

The main providers of chronic disease care to patients are primary care teams, which include their practice (GPs, practice nurses, health care assistants), community nurses, pharmacists, dieticians, opticians, podiatrists, and physiotherapists. The evidence that this type of care works well comes from other countries where care providers, in an attempt to improve chronic disease management, have registered patients with primary care teams and have found improvements in all dimensions of care (reduced inequities, higher quality care and better use of resources).<sup>ix, xx, xxi, xxii</sup>

Primary care teams will need to work alongside patients, making best use of the **Three Rs**;

- ✓ **R**egistration of a population of patients for whom primary care teams identify problems, co-ordinate care and help support their condition.
- ✓ **R**ecall of people to ensure they get the care they need by using prompts and reminders.
- ✓ **R**evision of patients to ensure they receive the best evidence based care and are supported to manage their condition

The new GP and Pharmacy contracts will go a long way to supporting this approach. The new GP contract, especially the Quality and Outcomes framework targets ten important chronic diseases. Based on past experience we have reasons to be optimistic that care for these conditions is going to improve considerably.





## Disease specific case management

For a minority of patients with more severe or unstable forms of chronic diseases there is strong evidence that specialist input into care can make a difference – especially those who have frequent admissions to hospital. These are patients for whom usual care from their practice and wider primary care team is insufficient and they find themselves repeatedly in hospital, or heading for long term complications. They need the input of **responsive specialist services**. There is good evidence about the impact of this kind of intervention for specific conditions, including heart failure<sup>xxiii</sup>, COPD and asthma<sup>xxiv</sup>, diabetes<sup>xxv</sup> and depression<sup>xxvi</sup>

### COPD and asthma

COPD is an under recognised, and under treated disease. It accounts for 0.8% of admissions, 2.3% of emergency admissions and 1.9% of bed days. A specific self care programme was very successful, demonstrating a 40% reduction in admission rates and improvements in all other aspects of care and quality of life.

Asthma is a common disease, with rising admission rates over the last 15 years, although these appear to be levelling off. Asthma accounts for 0.5% of all admissions, 1% of emergency admissions and 0.37% of all bed days in 2002/3

Certainly, disease management of asthma has an impact on symptoms and quality of life, whilst broader community based health service interventions (e.g. nurse led specialist input) also have an effect, reducing the need for emergency admissions by up to 38%.

### Heart failure

Heart failure is responsible for 5% of acute medical admissions and 10% of medical bed occupancy. Readmission rates for heart failure are among the highest for any common condition in the UK and have been estimated to be as high as 50% over 3 months. About half of these admissions may be preventable. CHF accounts for 0.6% of all admissions, 1.6% of emergency admissions and 1.9% of all bed days used.

The case for better disease management of heart failure is well established. Many trials have demonstrated improvements in terms of mortality, morbidity and resource use, including admissions. Admission rates are often reduced between 40%, and 90% with a 30% fall in length of stay. Indeed, the economic case appears compelling. In general, one-off access to specialist, often community based care, linked to self care and education, rather than telephone contact had the greatest effect.

### Depression

Depression is a common illness, with a prevalence of 10%. It is a disease with a relapsing course, and is increasingly managed as a chronic disease. Disease management has been applied successfully to depression, although improvements have largely been seen in improvements in quality measures (process and outcome) rather than utilisation or economic benefits.

### Diabetes

Diabetes is increasingly common: around 1.3 million people are currently diagnosed with diabetes. Diabetes accounts for 0.5% of all admissions, 0.8% of emergency admissions and 0.7% of all bed days

Applications of disease management programmes have shown improvements in disease outcomes and a 25% reduction in admissions and a 40% fall in bed day use. One US integrated delivery system, found an annual cost saving of \$75 per patient, but the savings were weighted at the end of a ten year period and required initial up front investment.

## Case management

Whilst many patients often have a single disease that impacts greatly on their life, for most patients there exists a complex mix of medical and social problems. For these patients a more holistic approach is required. They are often highly intensive users, or very highly intensive users of the health service, and simple problems amenable to early interventions (e.g. a fall or an acute infection) can lead to a rapid deterioration in their condition.

One project improving care of vulnerable patients is the Evercare project (supported by US United Health). In the US this project halved admission rates from patients in nursing homes. There were associated savings of \$103,000 per nurse practitioner. Other, mainly US based, projects have tried to reduce admissions in the elderly by implementing a multi-disciplinary and multi-agency approach to case managing frail elderly patients. Most have had good success with similar successes to the US Evercare project.<sup>xxvii</sup> Evercare is being piloted very successfully in the UK and is being rolled out to PCTs across the country.

The **London Older People's Collaborative** saw some dramatic changes in admission rates (47% fall) and A&E attendances (53%). These were often achieved by targeting a few high use people using a mix of case finding and case management. This is an example of case management from Brent PCT

### Before Case management

Initially presented in A&E 4 times over the last 3 months with falls  
Medically stable. Facilitated prevention of admission  
Care package, meals on wheels and personal alarm in situ  
At risk of recurrent falls, poor transfer technique  
Unable to access community transport or mobilise outdoors  
Oedema in both lower legs  
Older person felt lonely, isolated and depressed –  
“I tell people what I need but they don't hear me”.

### After Case management

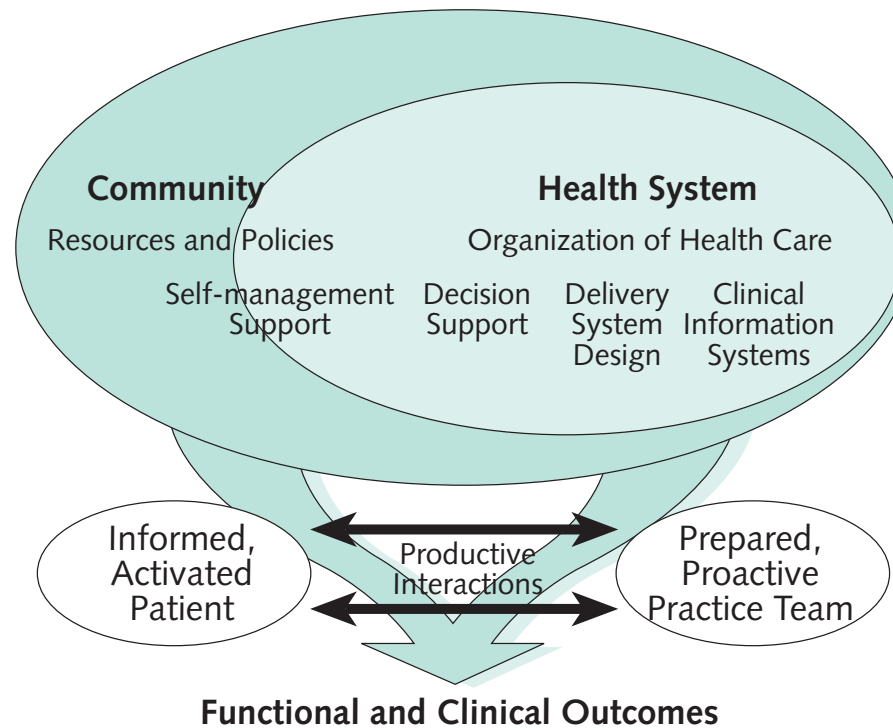
Easy-Care Assessment in own home.  
Established goals of the older person and worked jointly to achieve these.  
Listened to her voice and spent time understanding her needs.  
Contacted GP and District Nurse to review medication and to deliver incontinence pads.  
Spent time together to ensure receiving appropriate benefits.  
Arranged for mobile hairdresser and for ears to be pierced.  
Carried out a joint assessment with the Occupational Therapist (Collaborative Care Team) and applied for a new wheelchair to enhance outdoor mobility and activity – gave functional exercises.  
Put air into tyres of old wheelchair

Note that the numbers in this project were small but, in the opinion of the independent evaluation, reliable.

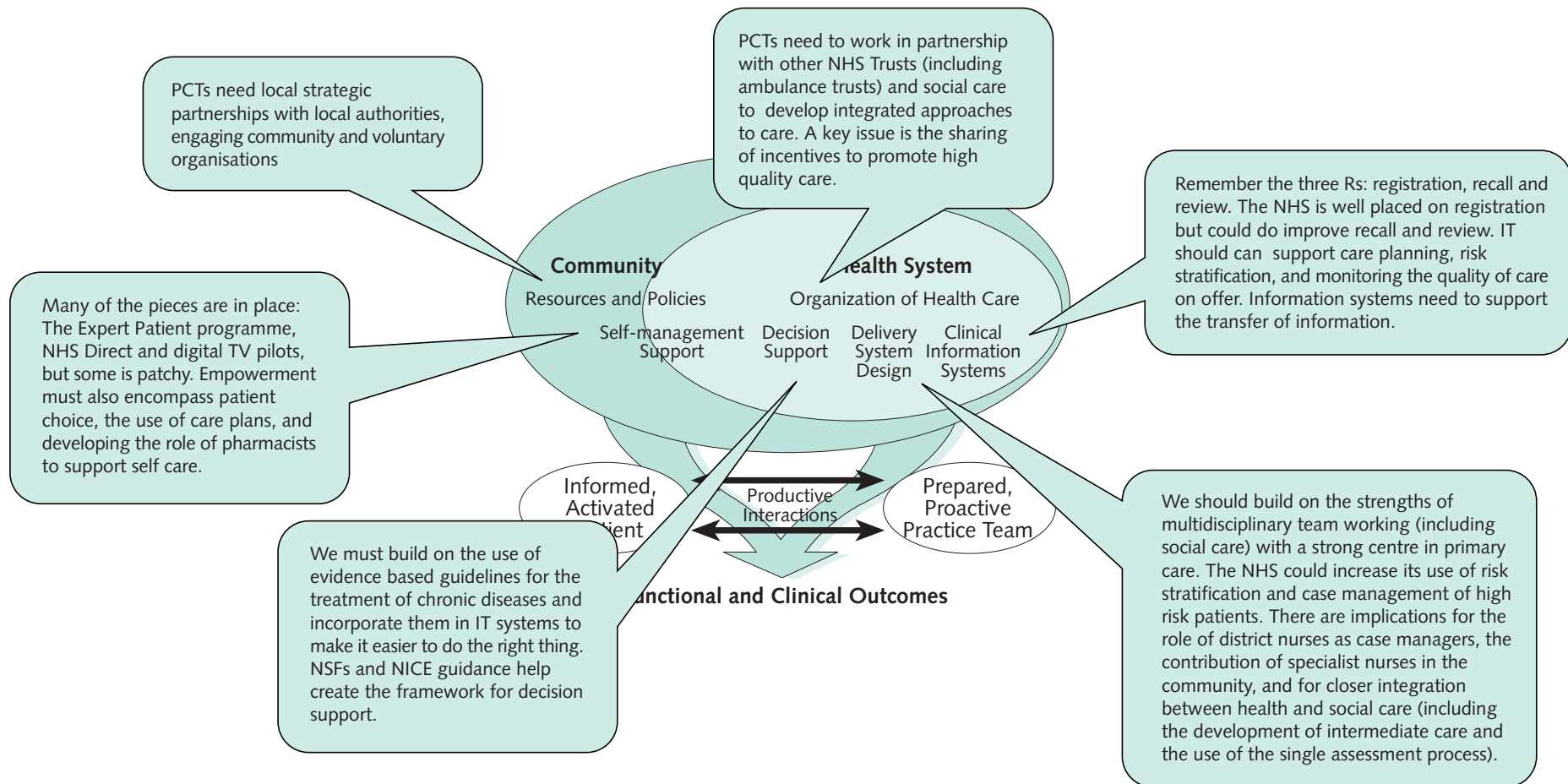


# How can the NHS put into place a system that better supports people with chronic disease?

From research we know a lot about how health care systems should work to best support people with chronic problems. There have been two recent meta-reviews of methods to interventions to improve medical care<sup>xxviii, xxix</sup>. Additionally, there are been reviews of integrated care pathways<sup>xxx</sup>, and others looking at the most effective methods of implementing chronic disease management<sup>xxxi-xxxiii</sup>.



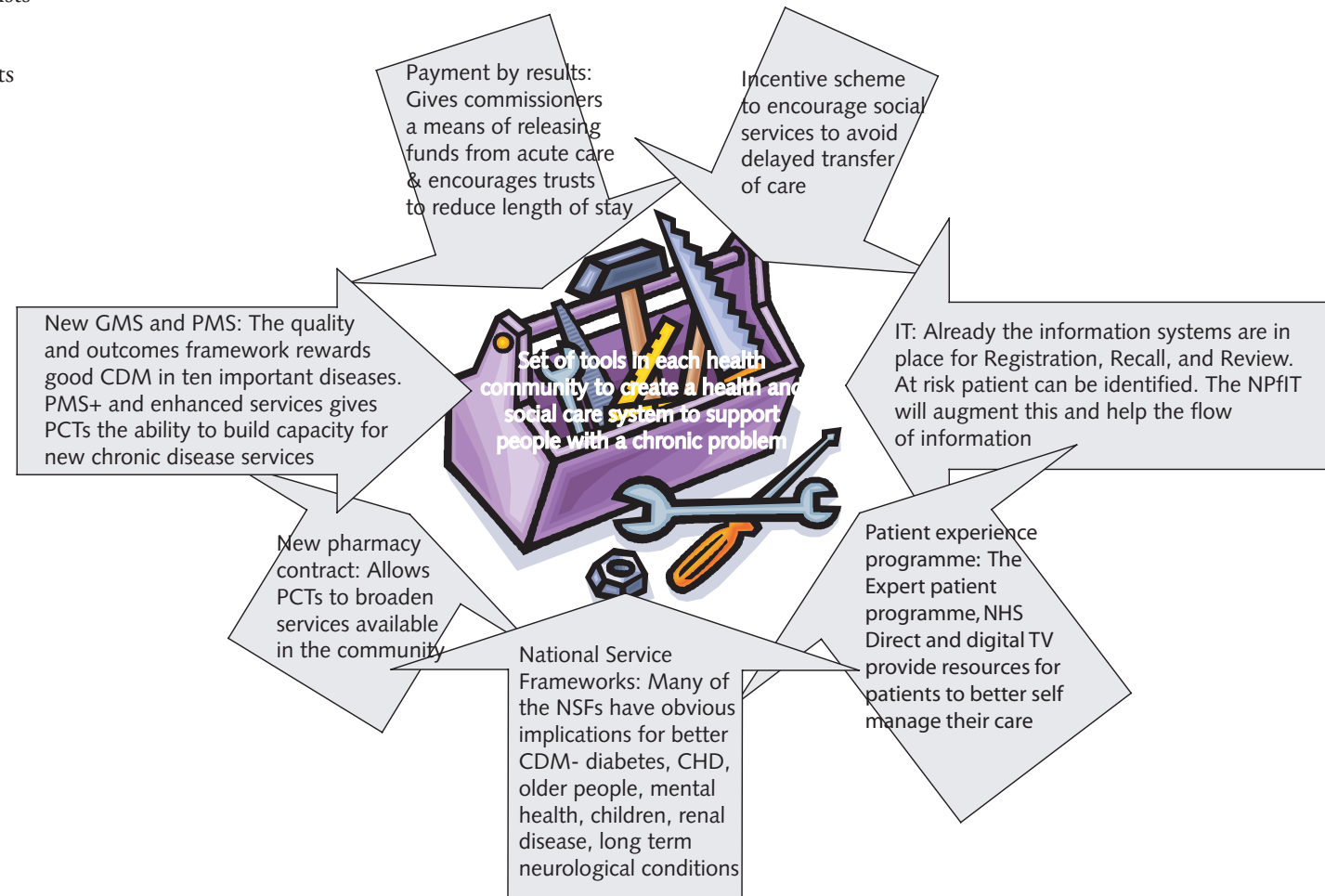
The most useful system for chronic disease management is the Chronic Care Model, developed on the basis of a literature search, tested on a panel of experts, and then subsequently researched and applied by Wagner and colleagues in Seattle<sup>xxxiv</sup>. This model has implications for the NHS. Whilst the NHS is starting from a position where many of the elements exist and where new policies like new GMS will support the development of the Chronic Care Model;<sup>xxxv</sup> The benefits of this model are most likely to accrue from a linked series of interventions rather than one or two initiatives.



## What are the system levers in each health community to help put a system in place to support people with chronic problems?

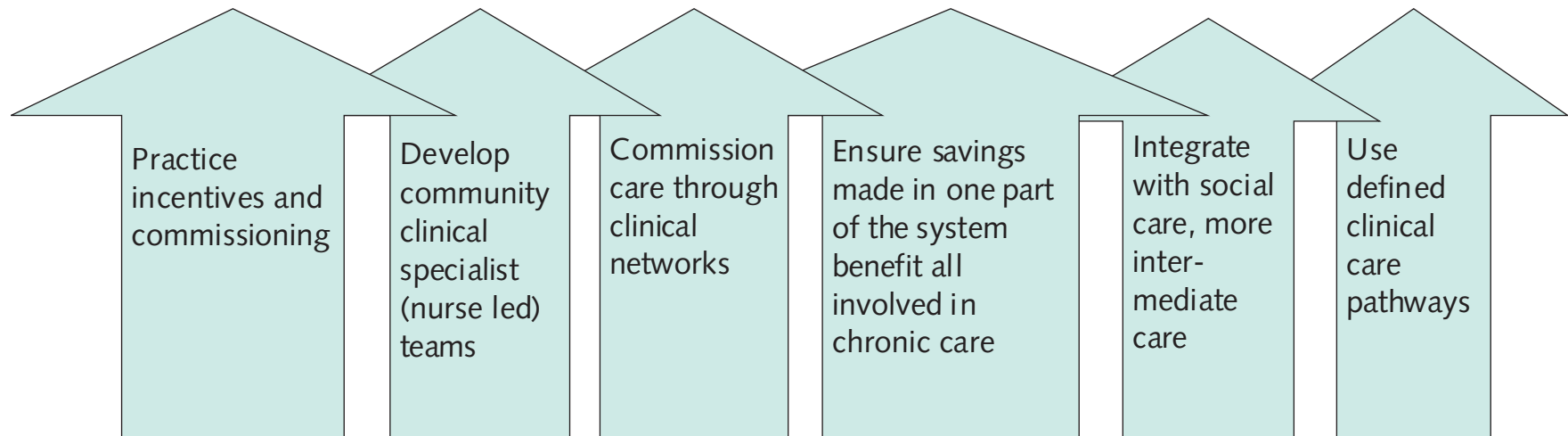
The NHS is fortunate in having a number of things in place that gives it a head start with managing chronic disease, these include

- Strong community nursing teams
- Strong general practice
- Patients on registered lists
- A network of community pharmacists



In addition, there are other elements health care communities could use to

## Improve support for people with chronic problems



# What are the likely benefits of better chronic disease management?

Most importantly, the main people to benefit from better chronic disease management are **patients** because they find:

## Increased

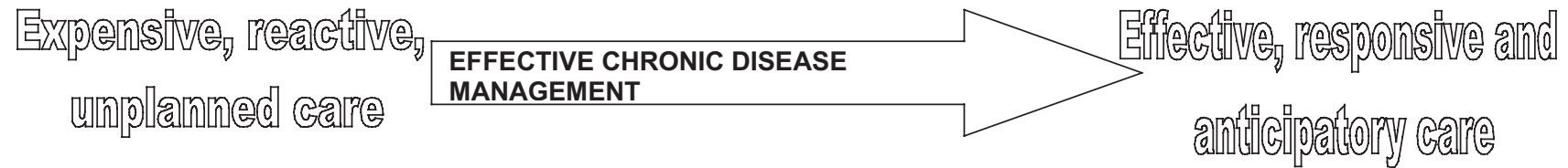
- ↑ Control of their own condition
- ↑ Feeling of well being
- ↑ Ability to cope day to day



## Decreased

- ↓ Complications from their chronic disease
- ↓ Unnecessary hospital admissions
- ↓ Sense of powerlessness

Health care communities and the NHS benefit because investing in chronic disease reaps health and financial dividends. In other words, there is a strong clinical case and a good business case. As we have demonstrated, the shift is towards making care more appropriate.



For instance:

The Wanless report, *Securing Our Future Health* (Interim Report) argued that for every pound invested in self care;



around £1.50 can be used in more appropriate ways and patients are actively engaged in their health care.



The economic case for disease management is more complex, but the improvement in quality of life for patients is undeniable. The growing evidence base (mainly from abroad, but increasingly from the UK) suggests that spending on case management is likely to bring financial as well as service benefits. These benefits include reducing the inappropriate use of acute beds. This will enable scarce resources like hospital beds and staff to be used on patients who require the specialist facilities of acute hospitals, but it depends on investing in primary and community services that will deliver these results.

One thing is certain, the benefits from chronic disease management will be greatest with a sustained and comprehensive effort.



## End Notes

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First published: May 2004

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