IPPR

POWERFUL PEOPLE

REINFORCING THE POWER OF CITIZENS AND COMMUNITIES IN HEALTH AND CARE
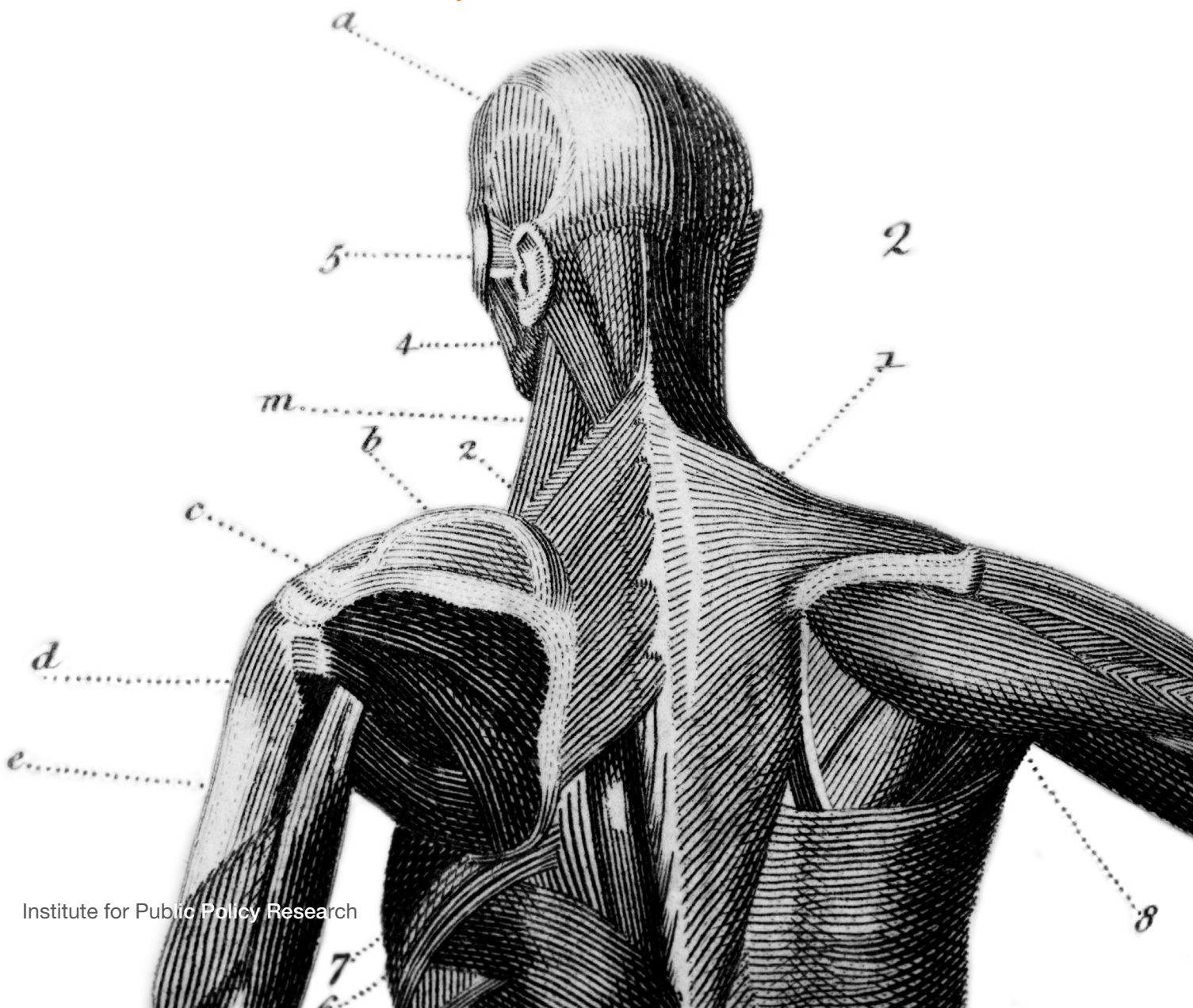
Institute for Public Policy Research

POSITIVE IDEAS
for CHANGE

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FOREWORD

Enhancing patient power in the NHS has been a long-cherished ambition. Successive governments have talked the talk but have not walked the walk when it comes to fundamentally changing the balance of power in the NHS. Today, patient power remains marginal rather than mainstream: the decisions that impact most on patients are still taken by clinicians, commissioners and policymakers in Whitehall.

This important report calls on the current government to change that. It rightly says that existing empowerment initiatives, notably the 'choice' and 'voice' agendas, are important if hospitals and GP practices are to become more responsive to their users. But it goes one stage further in arguing that, in a world where most healthcare demand comes from patients with long-term conditions, the focus must shift to creating health rather than responding to ill health. That means giving people the information, power and control to stay healthy, manage their conditions and choose their treatments. It identifies the new, empowering models of care that are emerging across the country, which bring about a fundamental shift of power from providers to patients. These models include social prescribing, the integration of care around the patient, peer support and care networks, asset-based community development, and technology-enabled care plans.

Today these innovative models are available only to a minority of patients. In the next few years, the objective should be to make them available to all of those who could benefit from them. As the report argues, there needs to be an acceleration of the process of giving patients personal budgets so that more of the money is put directly into their hands. That way NHS resources can be better used to design proactive care rather than it being spent on crisis management. New forms of technology – such as telehealth and telecare – have the potential to put real power literally into the hands of patients. Leaders at every level in the NHS should be prioritising how to harness this wave of democratic technological innovation not only to improve care but to change how healthcare works.

For decades, policymakers have focused on structural and organisational changes as the primary means of driving improvement. Other levers – competition, transparency, incentives – have also been deployed with some success. But a key lever of change has been missed: patient power. The opportunity now exists to make patients a key driver of change in the NHS. That will require, as this report outlines, an unprecedented shift in the culture, attitudes and skillset in NHS institutions and workforces. But if the NHS can rise to that challenge then it will help put it on a sustainable path. There is no more important task in the years ahead than for the NHS to stop treating patients as passive bystanders and instead to enlist them as active agents of change.

Alan Milburn
Health secretary, 1999–2003

Stephen Dorrell
Health secretary, 1995–1997

SUMMARY

The demands on the NHS have changed out of all recognition compared to those when the service was founded after the second world war. Then the system had to tackle communicable disease and broken limbs. Today the burden of disease has shifted to long-term chronic conditions, most of which are caused by unhealthy lifestyles. As a result there is now a wide consensus that our healthcare system needs to change from one focused on treating illness to one which also creates health.

In its *Five Year Forward View* NHS England has set out a number of ways of achieving this shift (NHS 2014a). In particular it has outlined a number of more integrated models of healthcare provision which are currently being developed around the country.

This paper argues that one of the key enablers of this shift is to give citizens greater control over their health and care. By giving citizens greater power in the system, services will have to be redesigned around their needs and aspirations. The evidence also shows that empowering patients improves health outcomes and could save money by supporting people better to manage their conditions themselves.

While politicians have long declared that empowerment should be at the heart of the NHS, most decisions are still made by large bureaucracies and clinical professions, rather than people and communities. Attempts to empower patients so far have focused on making acute services like hospitals more responsive, but we now need to give people greater control over their own health in their homes and communities.

There are promising and empowering models of care being tried out all around the country. These include: social prescribing models which address people's social, emotional and practical, as well as medical needs; brokerage and integration models which means that services are joined up around the person rather than people having to navigate fragmented service; peer support models which mobilise the knowledge, skills and empathy of people with similar conditions so that they can better manage those conditions themselves; asset-based community development models which focus on strengthening people's capabilities so they are less dependent on services and can lead independent lives; and technology-enabled care plans which provide people with the technology and data needed to better manage their condition themselves.

Nevertheless these models are at the margins of the system. What can we do to help them spread? We argue that five steps need to be taken.

1. We need to change the way money flows around the NHS. **We recommend that £4 billion of the new money the government will invest in the NHS over this parliament goes into a transformation fund** to invest in new models of care and drive change in the healthcare model provided throughout the country. **We recommend that money is put directly in people's hands by accelerating the spread of personal health budgets**, which should be an entitlement for all those with long-term conditions by 2020. More widely, local commissioners should provide funding for integrated healthcare providers based on capitated and outcomes-based funding.

2. **The government should embrace and take further the 'devo-health' agenda**. Power needs to be devolved down to local areas and to frontline professionals so that they are better able to redesign services around people's needs.

3. This agenda requires a profound change in clinical and healthcare cultures and mindsets. **We need to equip the healthcare workforce with the roles and skills required to provide these new models of care**, as well as moving to a coproductive culture in which decision-making is genuinely shared between patients and healthcare professionals.

4. Technology is key to putting more power, especially data, in citizen's hands, which will enable them to know more about their own health and act more effectively themselves to stay healthy and well. But the NHS is very poor at adopting and diffusing new technologies. **We call for a better adoption and diffusion mechanism for technologies**, such that it is easier to sell products into the NHS and such that the NHS itself is demanding innovation.

5. Empowerment is not just something that is given by the system: citizens themselves also need to play a role. While the government, employers and communities have a duty to act upon the social determinants of ill health, we all have a responsibility to live healthily. **This should be incentivised in the tax system, such as by increasing taxes on some high-strength alcoholic drinks**. A more active role for citizens should be promoted by helping them to be more involved in and prepared for care planning; by actively seeking to achieve the goals agreed; by sharing their health data with professionals from different service organisations; by getting involved in the community and by helping others; and by purchasing and utilising new technologies.

The NHS faces a challenge over the next decade of meeting growing and more complex demand within tight financial constraints. There are already many examples of doctors, nurses, managers, community workers and patients trying out innovative models of care that show how this challenge can be met. The task for policymakers is to ensure that we have a healthcare system that supports these empowering models and enables them to spread.

1.
INTRODUCTION

Don Berwick, a former healthcare adviser to US president Barack Obama, began his 2012 address at the American Hospital Association by recounting the story of the Choluteca River Bridge. The bridge, located in Honduras, was famous for its fragility: every hurricane which hit Honduras would cause the bridge to collapse and it would require rebuilding. In the early 1990s the government brought in specialist bridge builders from overseas and invested in the best new designs and materials. In 1998 Hurricane Mitch hit Honduras with winds of 180mph, waves of 44ft and record rainfall. As much as 70–80 per cent of the Honduran transport network was destroyed, including most bridges and secondary roads, amounting to $236 million in damage. However, unlike its predecessors the new Choluteca River Bridge survived intact. While this success was widely celebrated, it was a pyrrhic victory: the force of Hurricane Mitch moved the Choluteca River, changing its course. Choluteca was left with a bridge to nowhere.

The Choluteca River Bridge is a fitting metaphor for the NHS. Emerging out of the ashes of the second world war in 1948, the NHS is one of Britain's proudest 20th-century achievements. It has played an instrumental role in increased life expectancy, lower infant mortality, the elimination of many diseases and more widespread improvements in social and economic welfare. Indeed, the NHS is recognised as one of, if not the, best healthcare systems in the world: in 2014 the Commonwealth Fund ranked it first out of eleven Western equivalents, including the US which spends over 50 per cent more per head on healthcare (Davis et al 2014). Comparative studies have shown that the NHS scores highly on equality of access and healthcare utilisation, is effective at controlling costs and enjoys high levels of public confidence (Davis et al 2014, Reibling and Wendt 2011, Wendt et al 2011).

The NHS is a strong bridge, built around the right values. The problem is that the river it was created to cross is changing course. This is driven largely by demography: there is more demand on the health system as our society ages and we need to care for growing numbers of frail elderly people. Demand is not just larger, but is also more complex: 60 years ago the focus of the NHS was on broken limbs and infectious disease, today the big challenge is chronic illness. Diseases like heart disease, hypertension and diabetes are not easily treatable and are with sufferers 24/7. They cannot be adequately managed by clinicians delivering interventions in GP surgeries or hospitals, but require ongoing management by patients themselves, through changes in lifestyle, diet and exercise.

These transformations in population and disease mean that health and care services need to change radically. Most of the money we spend on healthcare is at the acute end, rather than where it should be: on preventing people from getting ill in the first place, or when they do get ill on helping them to manage their health better themselves. This means changing the locus of care out of hospitals and into people's homes and neighbourhoods. It means widening the scope of activity in our health and care systems, such that we are tackling the wider social determinants of health and mobilising a wider range of services and actors to help us do this, including the community, the third sector and industry.

As well as changing demand we face a tighter financial climate: across the developed world between 2000 and 2009 health budgets rose faster than economies grew (Morgan and Astolfi 2013). The financial crisis and subsequent

squeeze on government spending has brought an end to a period of buoyant health budgets. Over the last four years the NHS has had to live with a flat budget in real terms, when it has historically been used to 4 per cent average real terms increase in spending each year. NHS England estimates that rising demand and higher costs will produce a funding gap of £30 billion by 2020/21. The government has committed to raising an additional £8 billion in revenues for the NHS by the end of this parliament, which leaves the NHS with the need to increase its productivity by a historically unprecedented £22 billion over the next five years (Roberts 2015).

So, the challenge is to find ways of reforming a health and care system designed in 1948 so that it is both aligned with today's very different demands and able to perform successfully within the current financial constraints. There is considerable agreement on the destination: a system that is better at preventing disease, supports people to manage their conditions better themselves, is more accessible to patients and provides more care in the community (see NHS 2014a). There is less agreement about how to get there.

We identify the following five big enablers of this shift in our model of healthcare.

1. **Finance**: money needs to flow over time out of acute care and into 'health creation' (preventing and managing chronic illness). This may require some 'invest to save' measures that should be prioritised as part of the additional funding that is set to be allocated to the NHS in the forthcoming spending review. It will also require reforms to the way health and care is commissioned and to the way providers are paid.

2. **Integration**: our health and care system is still divided into primary and secondary, physical, mental and social care services. The fact that we now have so many people living with multiple chronic conditions means that we need services to join up around the person and provide a simpler and more personalised interface between the citizen and health and care professionals.

3. **Workforce**: the NHS workforce has grown by 160,000 whole-time equivalent clinicians since 2000, but the composition of the workforce has not always kept pace with changes in demand. For example, there has been increased job specialisation, but we know that rising numbers of patients with multiple conditions require more cross-cutting and generalist roles (see NHS 2014a). The NHS will need to think ahead in order to recruit and train a new kind of workforce.

4. **Technology**: breakthroughs in pharmaco-genetics should mean that we can become much better at predicting and preventing disease. Digital technology, such as wearable tech and electronic patient records, should mean that both patients and doctors will know more about a person's vital signs and can become much more effective at managing chronic conditions. Advances in robotics and artificial intelligence could make it much easier to support elderly and disabled people to live independently in their own homes. The key challenge is how the NHS can get better at adopting and diffusing these kinds of transformational technologies (Quilter-Pinner and Muir 2015).

5. **Empowerment**: the fifth big enabler of change gives citizens greater control of their health and care so that services will have to adapt and reform around their needs and aspirations. It is this through this lens that we focus this paper.

So, how much power do ordinary citizens have in the NHS? Our system has tended to empower large bureaucratic organisations and medical professionals rather than ordinary citizens. The big commissioning decisions are made by large organisations like NHS England and clinical commissioning groups. How care is organised and managed is decided by providers such as large NHS trusts and GP practices. Finally, the model of care is generally a medical one whereby doctors hold most of the knowledge and power and patients are too often seen as passive and uninformed consumers. This paper aims to show how we can shift power away from big bureaucracies and medical professionals and towards people and communities.

2.
WHAT DO WE MEAN BY EMPOWERMENT IN HEALTH AND CARE?

A person is empowered over their health and care to the extent that they can manage and make decisions about their health, shape and choose the health and care services they use and influence the wider social conditions that affect them, whether individually or through their relationships with others, so that they can lead the lives they want to live.

A person is disempowered, by contrast, if they lack the information and resources to manage and make decisions about their health and if they have little ability, either individually or in combination with others, to shape and choose the care they receive and the wider social conditions in which they live. Disempowerment manifests itself in depersonalised 'take it or leave it' care packages, unresponsive services and individuals isolated from wider networks of support.

This concept of empowerment is a capacious one, and can be differentiated from some more limited concepts of empowerment that are often deployed in healthcare debates.

First, power is not just something we exercise as individuals, but is something that can be expanded through our relationships with others. The rise of 'new public management' thinking across public services over the last 30 years has tended to privilege an individualistic view of the service user or consumer in relation to public services. This strand of thinking emerged from an understandable frustration with 'take it or leave it' monopoly provision in public services and a view that public services had fallen behind the private sector service economy in terms of responsiveness and consumer power. In light of this, reform measures focused on expanding the choice that we have as individual patients over which GP surgery to join or hospital to attend.

While these measures are necessary and important, to focus solely on the citizen as consumer is to take a reductionist view of the person in relation to public services. People's power over and enjoyment of public services is enhanced if those services understand and support the relational life around the individual. This is particularly important in such intrinsically relational services as health and care. So, for example, if a person never leaves the house and is lonely and isolated, they are likely to be significantly less empowered over their health, than someone with strong support networks. To take another example, some of the most effective and empowering public service programmes in recent years have been those that take a 'whole family' view, not just thinking about an individual service user, but about their relationships with their parents, grandparents and children as well.

Second, empowerment in health and care has tended to focus on giving patients more rights, information and choices so that acute healthcare services are more responsive to them. There has been far less focus on empowerment in the sphere of prevention – so that people do not get ill in the first place – and self-management – so that when they have developed a chronic health condition they can manage it effectively themselves.

Third, empowerment in health and care is not just about empowering people in relation to public services, but also about giving them the capability to exercise greater control over the wider social factors that affect their health. It is arguably as important from a heath point of view that a person has an influence over their housing and employment conditions as they do over the type of care they receive in hospital.

Fourth, empowerment over one's health is not necessarily enabling someone to 'maximise their utility' or to do what they want at any particular moment in time. For example, someone may want to act in such a way that is damaging to their health, by smoking or drinking too much or by abusing dangerous substances. There is a distinction between the freedom to act as one wishes in any particular moment, and a deeper notion of freedom as autonomy, understood as having a greater capacity to recognise one's fundamental interests and shape one's life accordingly. Without attempting to answer the substantial philosophical questions this distinction gives rise to, the definition of empowerment we set out above is capacious enough to recognise that giving people the ability to do what they want may not always be empowering.

We return to these conceptual questions later in this paper when we explore the variety of empowerment strategies that have so far been deployed in our health and care system.

3.
WHY EMPOWER PEOPLE IN HEALTH AND CARE?

Empowerment over one's health and care is both a good thing in and of itself, and because it tends to produce better outcomes for patients, particularly those with long-term conditions which require ongoing self-management.

3.1 Autonomy

Giving citizens greater control over their health and care is a good thing: autonomy, or the ability to exercise control over the forces that affect our lives, is an essential part of a good life. Any country wishing to enhance the wellbeing of its citizens should promote it.

It is this demand for greater self-determination that animated those who campaigned in the 1970s and '80s to close the large long-stay institutions that used to house thousands of people with disabilities and mental health problems. The coercive conditions, alongside the widespread abuse and poor practice that existed in such places, were shameful and rightly caused a shift in the 1980s and '90s towards providing greater 1980s and that existed in

Building on this shift in attitudes and practice, groups such as In Control called for disabled people and others receiving social care services to be given greater control of the services they used. Out of this movement personal budgets were born in the 2000s which gave people in receipt of social care services the ability to control their own budget and design their own care packages, including employing their own carers (Fox 2014).

In healthcare self-directed support is only now starting to break through into mainstream services, but there are strong grounds for extending it. Healthcare services should support people to lead independent lives, rather than forcing them to fit their lives around the services on offer.

So, there is a straightforward moral case for empowering people in health and care – but there is an instrumental case as well. Empowerment can produce better health outcomes, more satisfied citizens and much-needed financial savings.

3.2 Better health outcomes

Research has shown that patient 'activation [having the knowledge, skills and confidence to manage one's own health] is strongly related to a broad range of health-related outcomes, which suggests improving activation has great potential' (Greene and Hibbard 2012). This is because patients with chronic conditions live with their condition 24/7 and only spend a fraction of their time visiting clinical experts: the rest of the time they have to manage their condition themselves (National Voices 2014). It is also explained by the fact that a growing number of people live with multiple chronic conditions, which means that understanding and effectively managing their health is a complex matter in which the patient may know more at times than a doctor.[1]

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1   45 per cent of those with a long-term condition have more than one such condition. The majority of people aged over 65 have two or more long-term conditions; the majority of over-75s have three or more; and overall, the number of people with multiple conditions is rising (DH 2012).

A summary of the evidence on the impact of self-management and shared decision-making on health outcomes by the Health Foundation found the following (Ahmad et al 2014).

- Self-management programmes in areas such as mental health, arthritis, heart disease, lung disease, diabetes, asthma and stroke have all been demonstrated to improve patient self-efficacy.
- For self-management programmes, there is evidence of positive clinical outcomes for a range of conditions including arthritis, asthma, diabetes, hypertension, heart disease, heart failure, stroke and cancer. It should be noted that these improvements are not always consistent across different studies.
- Studies have shown that shared decision-making processes are more likely to result in people adhering with treatments and actions.
- The evidence of impact varies considerably across different conditions and different outcomes. Evidence tends to be strongest for improvements in self-efficacy and weakest for 'healthcare utilisation' (and therefore saving money). It is stronger for cancer screening and mental health, but noticeably weak for coronary heart disease.
- Taken as a whole the evidence base is mixed across conditions and outcomes for self-management and shared decision-making: some studies show positive impacts, others not. However, this is likely to reflect the practical and methodological issues such as poorly designed interventions, poor implementation and/or weak evaluation.

A major 2012 empirical study of the relationship between clinical outcomes and patient activation in Minnesota concluded that:

- patient activation was significantly related in the expected direction to 10 of the 13 patient health and utilisation outcomes
- patients with the highest level of activation were nine percentage points more likely to have systolic blood pressure within the normal range, compared with those in the lowest level of activation
- more activated patients were less likely to visit emergency departments, less likely to be obese, less likely to smoke and less likely to have cervical and breast cancer (Greene and Hibbard 2012).

3.3 Patient satisfaction

Research has shown that patients who are engaged in their health and healthcare – through health literacy, shared clinical decision-making and self-management – are more likely to say that their healthcare is of high quality, and are less likely to report experience of medical errors (Edgman-Levitan and Brady 2013).

In a comprehensive survey of the evidence base on patient-shared decision-making and satisfaction the Health Foundation found that:

- decision support aids have been found to help pregnant women by reducing anxiety, improving knowledge and reducing conflict
- decision support aids have also been found to improve satisfaction among A&E patients (Ahmad et al 2014).

In a survey of patients with long-term conditions for our earlier paper, Patients in control, IPPR found that people who were offered the least information and support to self-manage at the time of their diagnosis were least likely to be satisfied with the day-to-day management of their health condition (McDonald 2014).

3.4 Saving money

Healthcare systems across the developed world are facing a resource crunch: the demographic pressures of an ageing society coupled with the rising cost of

medicines are leading to rising demand and higher costs. Seventy per cent of healthcare spend in England goes on treating chronic conditions and people with chronic disease account for 50 per cent of all GP appointments (DH 2012). With rising longevity, these demand side pressures are likely to become greater in the years ahead.

Giving people the support and information they need to avoid getting ill, or when they have a chronic condition to self-manage it effectively, should save the NHS money by reducing demand on acute care. If people are not equipped and supported to self-manage, they are effectively left on their own and can end up with complications, health crises, preventable trips to the GP or A&E, avoidable suffering and even premature death. Around 20 per cent of emergency admissions to hospital are thought to be potentially preventable, and many of these involve chronic conditions (Blunt 2013).

The most robust evaluations of empowerment programmes focused on peer support and redesigned consultations have been estimated to reduce acute care costs by 7 per cent. Nesta estimates that this, which they describe as a conservative estimate, would save the NHS £4.4 billion a year across England (Nesta 2013a).

The Health Foundation has found that:
• self-management programmes can reduce visits to health services by up to 80 per cent
• a recent controlled trial of diabetes self-management programmes found that this reduced the odds of hospitalisation and significantly prolonged the time to the first diabetes-related hospitalisation
• although shared decision-making approaches can lead to longer consultations, in the long term they are associated with higher satisfaction levels and can reduce the need for further future consultations
• the evidence on medicine adherence from shared decision-making is more mixed (Ahmad et al 2014).

4.
EMPOWERMENT IN HEALTH AND CARE – THE STORY SO FAR

There have been many attempts to give ordinary citizens and communities greater power in our health and care system. In what follows we describe existing models, focusing on those that have been promoted across the whole system.[2]

4.1 Voice

There has been a succession of efforts to give patients a greater voice in the system, both individually and collectively. In 1974 community health councils (CHCs) were introduced to provide a source of community feedback and accountability. These were replaced in England by local involvement networks (LINs) and more recently by Healthwatch England, a national network of local consumer organisations.

The successor bodies to the CHCs were criticised by Robert Francis QC in his report on Mid Staffordshire NHS foundation trust, in which he found that locally at least they had not provided adequate oversight. It is yet to be seen whether Healthwatch England will develop into a stronger consumer champion. Local authorities also have a role in the scrutiny of the health services in their areas, through their statutory health scrutiny committees.

At the individual level, patients can have their voice heard by turning to the parliamentary and health services ombudsman if they have a complaint and seek redress for poor service. Moreover, there has been a proliferation in digital platforms performing a feedback function, such as Patient Opinion, which directly passes people's views on to health and social care providers, and brokers responses.

4.2 Choice

In the mid-2000s Tony Blair's government prioritised expanding patient choice in the NHS, most notably by giving patients needing an outpatient appointment the ability to choose which hospital they are referred to by their GP. This was put into effect through the Choose and Book electronic booking system. Academic studies have shown that these measures were effective at improving quality in NHS hospitals (Cooper et al 2011).

Patient choice has been extended over recent years and now includes:
- the right to choose your GP practice, subject to whether they are taking new patients or accepting patients from outside their local area
- the right to choose where to go for your first outpatient appointment, including which hospital and consultant-led team
- the right to choose an alternative hospital if you have been waiting for elective care for longer than 18 weeks (or two weeks in the case of cancer)
- the right to choose who carries out a specialist test if you need one
- the right to choose who to see for antenatal care, where you have your baby and who to see for postnatal care

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2   There are hundreds of other localised programmes, many of which exist as part of nationwide improvement networks. We refer to some of the leading examples in the next chapter on empowerment strategies. However, here we focus on those with system-wide ambition and reach.

- the right to choose between community health services, depending on local availability
- the right to choose whether or not to take part in health research
- the right to choose a personal budget for some long-term conditions
- the right to choose treatment available in the NHS in another EEA country.[3]

4.3 Rights

Overlapping with the push to provide patients with greater choice between service options and providers has been a wider push to provide patients with some basic rights or entitlements.

This process started in 1991 when John Major's government launched the Citizen's Charter, which aimed, arguably for the first time in any comprehensive way, to make public services more responsive to the public. The Citizen's Charter emphasised the role of citizens as customers of public services and who should expect certain standards, and the policy was intended to bring some of the consumer focus that had emerged in the private sector into the public sector. There was a charter mark to recognise excellence, as well as individual charters for particular services. These were applied across NHS hospitals as well as other major public services, setting out expectations in terms of information provision, choice between services, accessibility, equality and redress (PAC 2008).

In 2009 the Gordon Brown government sought to codify citizen's entitlements by introducing the NHS Constitution. The constitution lays out the objectives of the NHS and the rights and responsibilities of the different actors within it, including patients.

Citizen entitlements within the NHS Constitution
The NHS Constitution provides citizens living in England with the following rights:[4]
- to receive NHS services free of charge
- to access NHS services
- to expect the local NHS to assess and provide for local needs
- to go to other EEA countries for healthcare provided by the NHS
- to not be unlawfully discriminated against in the provision of NHS services
- to access designated NHS services within certain waiting times or if those waiting times are breached to choose an alternative provider
- to be treated with a professional standard of care, by appropriately qualified and experienced staff, in a properly approved or registered organisation that meets required levels of safety and quality
- to expect NHS providers to find ways to continuously improve
- to access drugs and treatments that have been recommended by NICE for use in the NHS, if your doctor says they are clinically appropriate
- to expect local decisions on funding of other drugs and treatments to be made rationally following a proper consideration of the evidence
- to receive the vaccinations that the joint committee on vaccination and immunisation recommends
- to be treated with dignity and respect, in accordance with your human rights
- to accept or refuse treatment that is offered, and not to be given any physical examination or treatment without valid consent
- to be given information about the test and treatment options available, what they involve and their risks and benefits

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3   Note that some but not all of these choice rights are legally enforceable (DH 2014).
4   These are abbreviated, for the full version see DH 2013.

- to have access to your own health records and to have any factual inaccuracies corrected
- to privacy and confidentiality
- to be informed about how your information is used
- to request that your confidential information is not used beyond your own care and treatment
- to choose your GP practice
- to express a preference for using a particular doctor
- to make choices about the services commissioned by NHS bodies and to information to support these choices
- to be involved in discussions and decisions about your health and care, including your end-of-life care, and to be given information to enable you to do this
- to be involved, directly or through representatives, in the planning of healthcare services commissioned by NHS bodies
- to have any complaint acknowledged within three working days and to have it properly investigated and various further rights throughout the complaint process, including the option of taking the complaint to the parliamentary and health service ombudsman.

4.4 Personal budgets

Personal budgets are perhaps the most radical of recent innovations to empower citizens in relation to public services. We describe them as radical because at their most extensive they hand public money to the citizen to directly purchase the care and support they want. This represents a radical break with the orthodox model of public service provision, through which we pay our taxes and elect governments to decide how to spend them on our behalf. With personal budgets, in particular with direct payments, we are given direct control of the public money allocated for our needs and can decide ourselves how to spend it.

Personal budgets have been offered to all those in receipt of social care since 2008. People can take their budget as:
- a direct cash payment which is paid into their account
- an account managed by the council which is spent in line with the person's wishes
- an account held by a service provider and managed by the person
- a trust held by a carer, friend of family member
- a mix of the above.

The funding must be used to meet the person's assessed needs, but within those parameters they can spend it as they choose: for example, to employ their own care worker, buy services from a private or voluntary agency, buy equipment or pay for adaptations, and pay for travel to a cafe or social club to meet friends and participate in social activities.

NHS England has committed to rolling out personal budgets in health through a pro-gramme of Integrated Personal Commissioning. Nine demonstrator sites have been selected to trial this programme, whereby people with complex needs can receive an integrated budget including for their social care and non-urgent health needs.[5]

4.5 Transparency

Empowerment models such as voice and choice require public bodies to be transparent with their performance data, so that activists, users and communities

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5   See the integrated personal commissioning prospectus: http://www.england.nhs.uk/wp-content/uploads/2014/09/ipc-prospectus-updated.pdf

can hold them to account. Digital technologies have massively increased our capacity to generate, analyse and distribute such data.

The government's open data agenda means that as much publicly released data as possible should be made freely available for everyone to use or reuse in any way they like. More health data is now made available online and is structured so it can be more easily used by citizens. This means that a light can be shone on variations in performance, aiding patient choice and public scrutiny, while also putting direct pressure on providers to up their game.

For example, it is now possible via the My NHS website to find:
- GP surgeries comparable by safety and effectiveness, caring outcomes, responsiveness, care of the over-75s and chronic disease management
- hospitals comparable by CQC inspection rating, A&E waits, mortality rates, staff recommendations, infection control and cleanliness, number of patients waiting more than 52 weeks and the so-called 'friends and family' test
- individual consultants by specialism with patient mortality rates from their back history of operations and an assessment as to whether the figures lie within the expected range.[6]

4.6 Education

It has long been recognised that the biggest experts in chronic conditions are the people who live with them day in and day out. There have been educative programmes to support patients to self-manage their conditions, most notably the expert patients programme (EPP). This programme offers free courses to anyone with a long-term condition, and run for six weeks covering how to deal with pain and tiredness, coping with depression, relaxation techniques and exercises, healthy eating, communication with family, friends and healthcare professionals, and planning for the future. The sessions are run by tutors who themselves have chronic conditions.

An evaluation of the EPP found that it did lead to increased self-efficacy and energy, plus small gains in psychological well-being and partnerships with doctors. There was an overall reduction in service utilisation, which led the researchers to argue that it was a cost-effective programme (Rogers et al 2006).

Each of the models mentioned above – voice, choice, rights, personal budgets, transparency and education – has an important role to play in empowering people in their own health and care. Nevertheless, taken as a whole, they have not gone far enough. In the next chapter we show why.

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6   See: https://www.nhs.uk/service-search/performance/search

5.
WHY EXISTING APPROACHES HAVE FALLEN SHORT

Despite recent programmes aimed at empowering citizens, NHS patients still do not feel sufficiently empowered or involved. For over a decade around half of inpatients asked in the NHS Inpatient Survey have said they would like more involvement in decisions about their treatment and care. There are similar figures for those using mental health services. Only 17 per cent of carers responded that they were always involved as much as they wanted to be in decision-making. While 38 per cent of respondents to the survey said that when they were discharged they did not fully understand the side effects of the medication they had been prescribed (Ahmad et al 2014).

IPPR's own research supports this picture. In our previous paper Patients in control we presented the results of a survey of over 2,500 people with long-term conditions. We asked them about their attitudes towards and experience of the management of their conditions, and discovered the following (McDonald 2014).

- While the majority of respondents (63 per cent) were satisfied with the day-to-day management of their conditions, of the 37 per cent who were dissatisfied a high proportion had not been given information and support at the time of diagnosis.
- Over three-quarters of respondents (77 per cent) told us that more of their healthcare could and should be managed independently at home – but they said that a lack of support and information was holding them back from doing so. This is a missed opportunity for both patients and the health service.
- We asked whether they had been offered a range of potential support and information when they were diagnosed with their condition and we found that few had been: none had been offered a personal budget; just 4 per cent had been offered apps or websites; 4 per cent devices for self-monitoring; 5 per cent a care plan; 7 percent peer support; 9 per cent coaching or education; 11 per cent information about local services and support; 14 per cent a single point of contact; and 40 per cent information about their condition.
- In all, 53 per cent of our respondents said they had been offered none of the above.

These findings show that, despite the political emphasis on empowering patients in recent years, empowerment has remained at the margins rather than at the centre of our health and care system. There has been no fundamental change in where power lies in the NHS.

There are four main reasons why existing approaches have fallen short in terms of systematically empowering patients.

5.1 The focus of reform has been on the acute sector

`Acute`

Figure 5.1 maps existing national empowerment models along two axes: the vertical axis shows 'reach', that is, a very rough estimation of whether they have reached a larger or smaller number of people, and the horizontal access shows whether they empower people in relation to acute healthcare services such as hospitals or family doctors or in the wider realm of 'health creation', whereby people are trying to stay healthy, either avoiding illness or managing their chronic conditions effectively.

Most of the political energy around empowerment over the last decade has been put into making hospitals, consultants and GPs more responsive to their patients. For this reason the empowerment models that reach the most people are clustered around the acute sector: the entitlements and choices set out in the NHS Constitution and in the Choice Framework, backed up by data transparency tools such as My NHS and Patient Opinion. Those tools do not exclusively cover acute care services – they do take feedback for community health and social care services for instance – but most of their work involves feedback from hospital and GP patients.

This is a major weakness in the current empowerment architecture, given that most of the demand of the health and care system is generated from chronic conditions which could either be prevented or managed more effectively in the home and the community.

Those models of empowerment that operate at the 'health creation' end of the spectrum score poorly on reach. Healthwatch and health scrutiny have relatively low levels of participation. The expert patients programme has wider reach, but even that suffered from reports of poor uptake and attendance, with many PCTs failing to fill their courses.[7] Personal budgets score higher on reach, in particular because of their spread through the social care system. However, they have yet to penetrate mainstream NHS provision.

The key insight here is that if we are to deepen and widen our approach to empowerment, we should focus our energies on empowering more people in the arena of health creation.

Figure 5.1
Empowerment in health and care: the reach and location of existing approaches
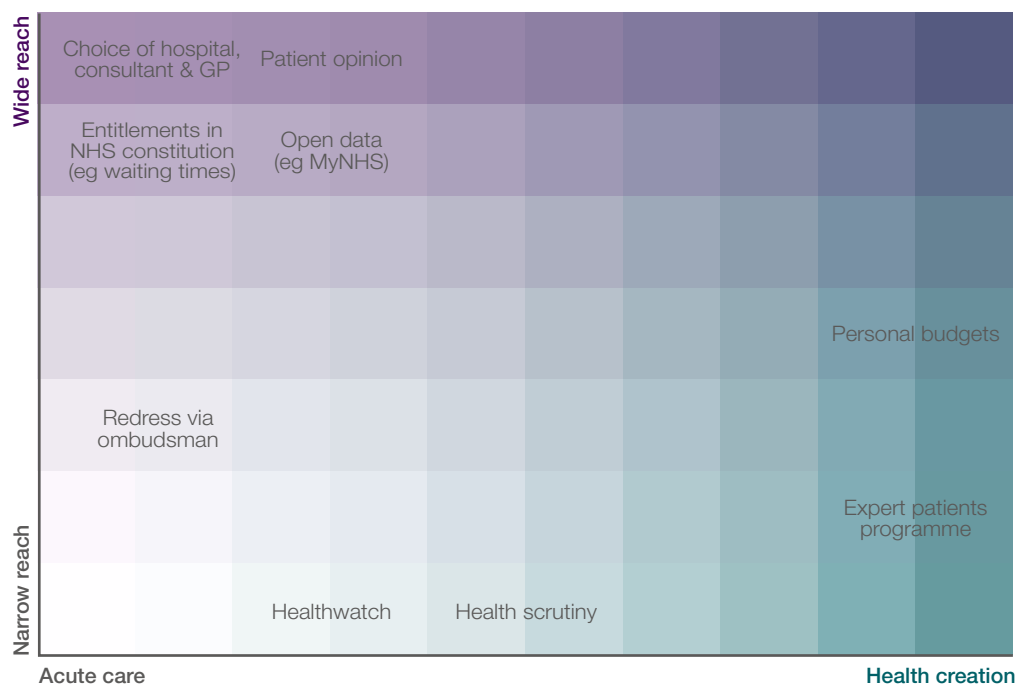
7   For the evaluation document, see: http://www.population-health.manchester.ac.uk/primarycare/
     npcrdc-archive/Publications/FINAL_PROJECT_REPORT.pdf

5.2 We have focused on empowering individuals independently of their relationships and networks

Individualistic

Figure 5.2 shows that the main empowerment strategies pursued by policymakers have focused on empowering the individual, through choice, rights and redress. This is unsurprising given the consumer choice focus of public service reform interventions since the 1990s.

The expert patients programme does bring people together through the courses it puts on, but it is largely focused on providing individuals with day-to-day skills rather than developing peer support. Personal budgets, as we describe in the next chapter, are in many ways inherently relational because the services they are used to purchase are relational services, such as hiring home help, paying someone to help with the shopping, or joining a social club. They also have potential as forms of collective empowerment where people can jointly purchase support: however, these kind of approaches are in their infancy (Fox 2014). Both Healthwatch and health scrutiny provide collective forms of voice but as we have seen they have relatively limited reach.

This focus on the individual consumer isolated from their wider relationships is problematic because people's networks are critical in determining their ability to manage their own health and care. Family and friendship networks play an important role in influencing behaviours. Analysis of the Framingham Heart Study, for example, found that social networks had a major impact on people's propensity to smoke or be obese: when a Framingham resident became obese his or her friends were 57 per cent more likely to become obese too. If a friend starts smoking, your chance of lighting up increases by 36 per cent (Thompson 2009).

Practitioners have been inspired by this insight to develop 'whole family' or 'whole network' approaches to preventing illness and supporting people once they have developed health conditions.

Figure 5.2
Empowerment in health and care: individual versus collective approaches
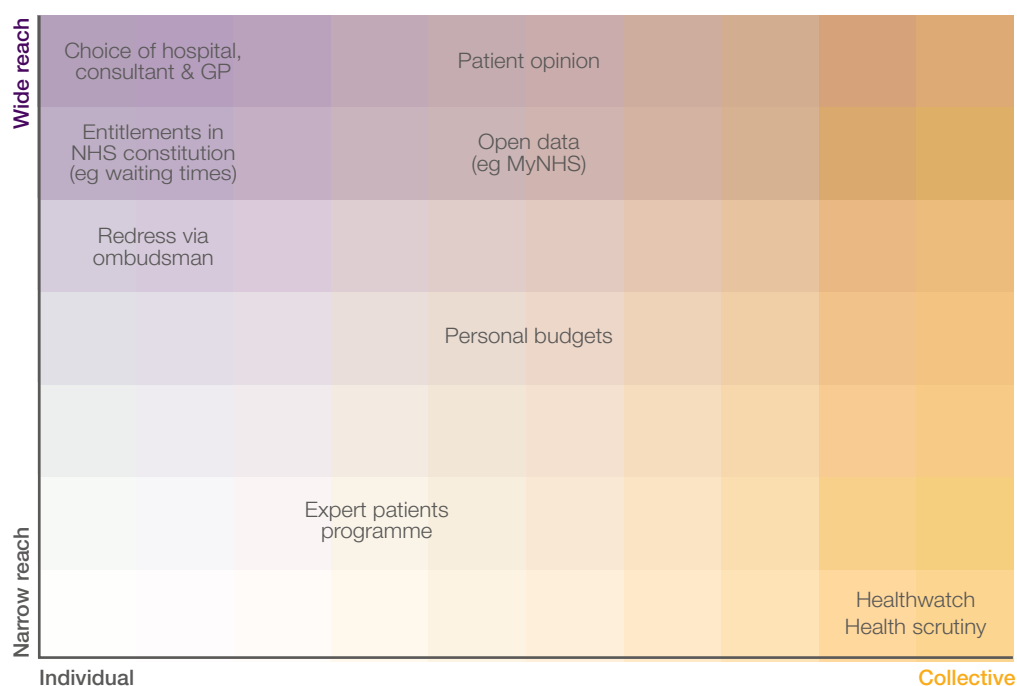
For example, Open Dialogue in Finland is a social network-based approach to dealing with mental health problems. It works with families and their social networks, and is delivered in the home where possible. The aim of this model is early intervention in the first stages of psychosis, to ensure that cases do not become chronic. The model is based around open family or network meetings, and it involves whole networks in providing help. It also ensures continuity of personnel: the same social worker stays with a family throughout the intervention, so that trust, knowledge and relationships can deepen. The service has achieved very high recovery rates – around 75 per cent of those who experienced psychosis have returned to work or study within two years, and only around 20 per cent are still taking antipsychotic medication at the two-year follow-up. These results are among the best in the developed world (Muir and Parker 2014).

Supportive social networks are also critical in the self-management of chronic conditions. Vassilev et al (2013) found that access to social networks provides people with long-term conditions with everyday sources of practical, emotional and illness-related support. Those who lacked extended and diverse networks can find it more difficult to manage their conditions effectively.

5.3 Approaches to empowerment have focused on empowering users in relation to individual services rather than on empowering them in the round.

Fragmented

Policymakers have generally focused on making individual health services more responsive to the citizen (see figure 5.3). This can of course be important: for example, providing an outpatient with a choice of consultant-led team or hospital for their operation, or laying out a clear redress mechanism if a person has a complaint.

However, the complexity of living with chronic conditions makes approaches built around a single service inadequate. In a world where most people with a chronic condition have more than one, one of the most disempowering features of the service landscape is the fact that it is so fragmented, with mental and physical health operating in different silos, health and social care separated and people having to see different specialists about different aspects of their health.

This complexity exists not merely in the way services are provided, but also because of the complex and interconnected factors that can impact on a person's health, including their housing, their employment status and their family and friendship networks. We need to take a more holistic approach.

To adequately comprehend and respond to people's complex and individual lives, services need to understand the whole person. This involves considering not just their power in relation to public services, but also their access to wider networks and resources in the community. As we shall see in the next chapter personal budgets have the potential to enable such an approach particularly if accompanied by holistic care planning and by integrating budgets from across social care and healthcare.

Figure 5.3
Empowerment in health and care: individual services versus 'whole-person' approaches
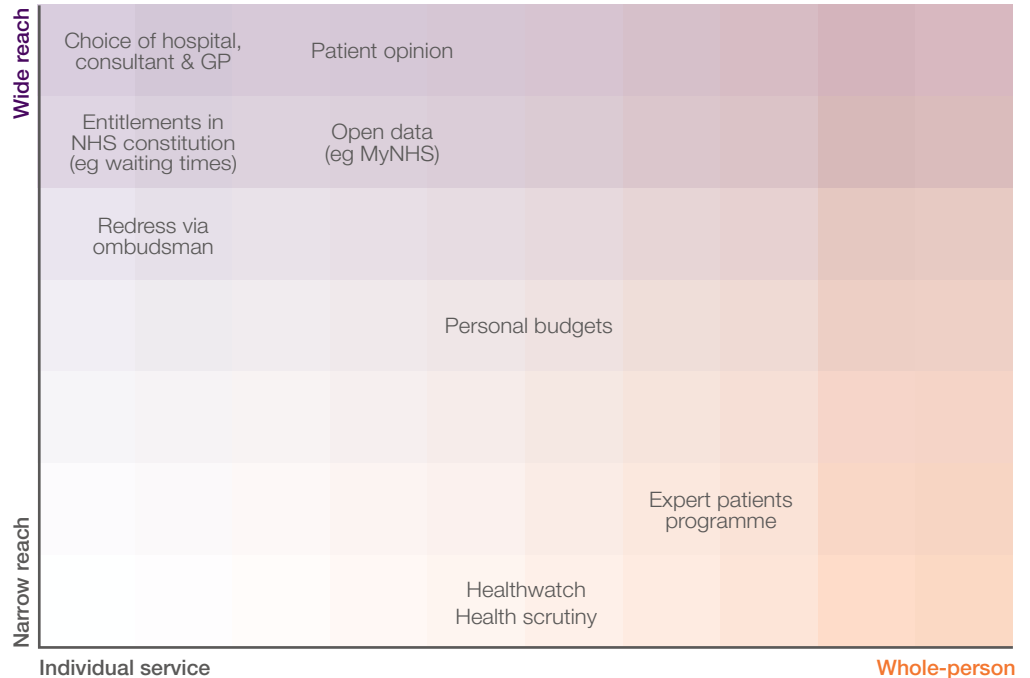
5.4 Empowerment models have focused on responding to a person's needs rather than developing their capabilities

> **Needs-based**

Empowerment models such as choice and entitlements have generally been seen as ways of better responding to a person's needs, rather than considering their capabilities. This is common across public services in developed countries, where services have been established with a 'deficit' mindset: hospitals exist to provide patients with medical treatment at times of acute need and doctors exist to diagnose illnesses and provide medications.

The 'asset-based community development' approach, which originates in the US, takes a different starting point: this rejects the view of the citizen as principally a 'service user' with needs that the state must meet. This approach tends to infantilise and disempower people, creating dependency cultures, in which people's best hope for improving their lot is to wait for a paid professional to step in. Instead, asset-based approaches see capabilities in everyone and seek to mobilise these. In particular they seek to mobilise people's 'relational power': the collective power to achieve social change that is developed when neighbours or fellow citizens come together to achieve their goals.[8]

Such approaches are still generally 'counter-cultural' in our system, but some moves in the direction of 'shared decision-making' share the same starting point. In particular, care planning under this model must start by discussing a person's needs and aspirations and then look at what resources are available to help meet

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8   For example, see the asset-based community development model: http://www.abcdinstitute.org/docs/
      What%20isAssetBasedCommunityDevelopment(1).pdf

them, taking into account their own skills and capabilities, as well as resources from the community before then looking at what can be provided by the state.[9]

The next two chapters explore how these dynamics can be challenged and changed.

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9   For example, see McNeil and Hunter 2014 on local area coordination in the state of Western Australia.

6.
EMPOWERING MODELS OF CARE

This chapter focuses on models of care that actively empower citizens in the ways described above. There is no single empowerment model in health and care but rather a whole range of care models that can give people, and particularly those with chronic conditions, greater control. The care models described in this chapter embody many of the characteristics of our notion of empowerment described at the start of this paper and address the deficiencies within the existing empowerment initiatives as highlighted at the end of the previous chapter. We use the same headings as in chapter 5 – acute, individualistic, fragmented and needs-based – to directly highlight how they improve empowerment.

6.1 Model 1: Social prescribing

Acute   Needs-based

Challenge addressed by this model: to move beyond the medical model and empower people by giving them access to the wider social resources to improve their health and wellbeing.

Social prescribing is 'a means of enabling primary care services to refer patients with social, emotional or practical needs to a range of local, non-clinical services, often provided by the voluntary and community sector' (OPM 2013).

Social prescribing is based on the recognition that good health is not just a product of medical treatment, but derives from wider social factors too. So, for example, regular exercise is critical in keeping blood pressure low and reducing the risk of cardiovascular disease. In another example, strong networks of social support have been shown to reduce the risk of depression and mental illness. It is estimated that loneliness is at least as bad for our health as smoking (Worrall 2012).

In practice social prescribing means GPs much more systematically referring their patients to organisations in the community who can help them achieve their goals in non-clinical settings. This model is recognised as important but is at the margins of the current system: 90 per cent of GPs, according to a survey by NESTA, believed that their patients would benefit from a social prescription, but only 9 per cent of patients said they had received one (Nesta 2013c).

Case study: Social prescribing in Newcastle
The Newcastle social prescribing project (2011–2013) set out to develop a network of non-clinical services to which health professionals could refer people with long-term conditions. It also sought to raise awareness and equip medical professionals to make best use of the service.

The delivery model was to refer patients to five link organisations, with expertise across older people, carers, lifestyle change and mental health. This simplified the referral process for GPs, while leaving link organisations able to refer on to others if appropriate. Each organisation had a link worker whose role was to support patients with goal setting and buddying, self-care and signposting for information, advice and support.

The need for awareness raising was shown by a survey of Newcastle GPs that revealed 84 per cent of GPs believed that the voluntary and community sector had a role to play in supporting their patients, but only 6.5 per cent felt they knew enough about the sector to work effectively alongside it.

Over the course of the project there were 124 referrals: 52 per cent were referred for physical health, 49 per cent for mental health, 40 per cent for lifestyle change, 30 per cent for social networks, 8 per cent for finance and 5 per cent for employment.[10]

The linkwork organisations made the following referrals: 36 per cent to HWN Health Trainer Service, 35 per cent to HWN Exercise Referral, 17 per cent to Age UK and 9 per cent to Carers Centre.

Over two-thirds of referrals (70 per cent) engaged with a link worker, 91 per cent of whom set goals; 41 per cent achieved their goals, 59 per cent did not; 69 per cent of people referred experienced an increase in their mental wellbeing score (based on the Short Warwick and Edinburgh Mental Wellbeing Scale) and 64 per cent achieved increased confidence in managing their condition.

Source: ERS Research and Consultancy 2013

6.2 Model 2: Brokerage and integration

Fragmented   **Needs-based**

Challenge addressed by this model: the fragmentation of health and care services which prevents them from focusing on the 'whole person'.

The complexity of today's health conditions, with so many living with multiple morbidity, caused by a variety of biological and social factors, means that services need to be joined up around the person. At the moment health and social care services are generally fragmented across a number of dimensions.

- **Organisations:** primary, secondary, community and mental healthcare are provided by different organisations, each of which is accountable for doing different things and responsible for only a partial element of a patient's health.
- **Clinical practice:** observations and treatments are generally undertaken separately by different organisations and specialists. This can mean that the interactions between different aspects of a person's health can be missed and that patients have to navigate and negotiate between lots of different parts of the system.
- **Data:** there is poor information sharing and an inefficient referral system, which adds cost and is ineffective for the patient. Tackling this means thinking about the interoperability of information systems, for example across primary and secondary care, and giving different professionals in different parts of the system the ability to access patient records. Concerns about data protection often inhibit this kind of data sharing.
- **Finance:** funding is provided to the separate care organisations in their silos – primary, secondary, community and social – each with different incentives. This makes moving money around the system to meet care needs difficult and controversial.

This fragmentation often means that many people with complex needs are passed from pillar to post, with each individual service engaging with them on its own terms, but often none of them providing the deeper, more sustained and personalised support required to deliver high-quality care and empower the patient.[11]

The most effective way of addressing these problems is through the integration of the various parts of the health and care system, but there are numerous integration models. We focus on two at opposite ends of the integration spectrum.

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10   Referrers could give more than one reason for referrals.
11   For a more in-depth exposition of this argument about complexity and the flaws of disconnected services see Muir and Parker 2014.

The first example is the brokerage model. Brokerage means that a person with complex needs is allocated or chooses a key worker with whom they can work over a sustained period of time. In our survey of people with long-term conditions we found that 75 per cent said they would find a single named contact useful, and 57 per cent thought that having a named contact for telephone support and advice would reduce the number of times they saw their GP, went to hospital or used A&E services. However, only 14 per cent said they were offered this when diagnosed with their condition (McDonald 2014).

A broker is a single point of contact, but it is more than that – it is someone who can really understand a person's needs and aspirations and with whom they can develop a deeper relationship than is normally afforded by single-service fleeting encounters. That person does not just 'signpost' but also acts as an advocate, able to work with the existing service landscape to bring services together into a coherent and personalised care pathway.

Brokerage typically involves the following elements:
- a key worker able to develop a relationship with a person over a sustained period – this worker may work for a public service or work for the community and voluntary sector as part of a commissioned brokerage service
- referrals by clinical and other professionals to the key worker when someone presents with an acute problem that is related to complex needs
- goal-setting and agreement of a plan to achieve those goals, identifying what the person will do for themselves, what support is available in the community and what services can contribute
- intensive support to help a person to achieve their goals
- advocacy with services to join up and personalise how they work with a person, helping them to achieve their plan.

Case study: Age UK brokerage in Cornwall
Age UK have developed a front-end integrated care model which has been piloted in Cornwall with great success.

GPs and others refer older people most at risk of hospitalisation to an Age UK personal independence coordinator. This coordinator works with the older person to find out what their goals and aspirations are – which, for example, may be a desire to walk their dog again or join a local social group.

The coordinator identifies those services that will provide support to meet those goals and work with existing services so that they 'wrap around' the person, helping with a range of things such as benefits advice, social activities and home help, all part of a coherent personal plan. The care plan is developed by the older person and reviewed regularly by a multidisciplinary team based in a primary care setting.

Each older person is also allocated a community volunteer who works with them intensively for 10 weeks to do things like improving their confidence in getting out and about and engaging in social activities.

In the first year 100 older people were helped, of whom 60 per cent were women and 40 per cent men, with a mean age of 83. Using the Short Warwick and Edinburgh Mental Wellbeing Scale, a 23 per cent average improvement was observed among older people in the cohort and there were 30 per cent fewer non-elective hospital admissions.

Age UK calculates that for every pound spent on this brokerage approach, £4 is saved for the health and care system. There are very high satisfaction rates and one in 10 of the older people on the pathway have actually ended up volunteering to help others.

Source: Age UK 2014

The second example worth highlighting, which is a natural progression from a simple brokerage system, is full integration (also referred to as deep integration). This is significantly more complex, time consuming and costly to deliver than brokerage, but is likely to provide better and more holistic care. It involves breaking down all of the different dimensions of fragmentation within the current system – organisational, clinical, informational and financial – to merge various existing functions performed by the state. Perhaps the most advanced example of this type of integration in the UK is being undertaken in Torbay – although there are many other examples being undertaken via the Vanguard Scheme and NHS Five Year Forward View – which has seen the patient placed at the heart of the organisational principle of the NHS.

Case study: Health and social care integration in Torbay and South Devon
Torbay and Southern Devon Health and Care Trust is an integrated health and adult social care organisation providing care for over 350,000 people in the region. It is one of the most advanced case studies of integration in the UK and points the way for the rest of the NHS. It brings together frontline health and social care staff such as district nurses, occupational therapists and social workers to provide holistic care from a range of different premises across Torbay and South Devon. Furthermore, it not only benefits from full physical integration but also clinical, technological and monetary integration (pooled budgets) as well.

This helps to deliver empowered patients as it is more consistently able to provide the right care, in the right place, at the right time for each specific patient. This is because the organisational principle of this integration model is the patient. The care model was built around the needs of 'Mrs Smith', a fictitious 80-year-old service user with multiple chronic health conditions. Focus groups identified how fragmented care previously failed 'Mrs Smith' and co-design with patients set out how new integrated care could address these problems.

The results of this reform have been well documented:
- the daily average number of occupied beds fell from 750 in 1998/99 to 502 in 2009/10
- emergency bed day use in the population aged 65 and over is the lowest in the region at 1,920 per 1,000 population compared with an average of 2,698 per 1,000 in 2009/10
- emergency bed day use for people aged 75 and over fell by 24 per cent between 2003 and 2008 and by 32 per cent for people aged 85 and over in the same period
- delayed transfers of care from hospital have been reduced to a negligible number and this has been sustained over a number of years
- since 2007/8, Torbay Care Trust has been financially responsible for 144 fewer people aged over 65 in residential and nursing homes
- there has been a corresponding increase in the use of homecare services, some of which are now being targeted on preventive low-level support
- the use of direct payments is one of the best in the region
- in 2010, the Care Quality Commission judged Torbay to be 'performing well' having previously been struggling to deliver high-quality care.

Source: Thistlethwaite 2011

6.3 Model 3: Peer support

Individualistic   **Needs-based**

Challenge addressed by this model: strengthening social networks so that people with chronic conditions are able to provide support to one another, enabling them to live more independently and reduce their risk of complications and use of acute care services.

Peer support mobilises the knowledge, skills and empathy of people with similar conditions so that they can better manage those conditions themselves. In our

survey of those with long-term conditions 61 per cent said they would find access to peer support useful, but only 7 per cent said they were offered this when diagnosed with their condition (McDonald (2014).

Nesta distinguishes between four types of peer support:

1. activity-based – where people share experiences and overcome challenges as a group
2. one to one – where a pair of people provide ongoing support by 'buddying up'
3. befriending – generally this is not with a person with a similar condition, but is a way of helping someone through a transition to, for example, a new home or neighbourhood
4. locality-based – where peer support networks develop around a community hub, such as a lunch club or community centre (Temperley et al 2013).

There is evidence that peer support:

- can reduce emergency admissions: a US trial that assessed seven weekly group sessions of peer-facilitated self-management education found there was a reduction in emergency admissions and outpatient visits, improved health behaviours, reduced symptoms and improved health status, and that after two years there were reductions in service use and emotional distress (De Silva 2011)
- can save money: another study estimates that befriending schemes in mental health can save £270 for every £85 invested, taking into account wider quality of life measures (Knapp et al 2011).

Case study: Leeds neighbourhood networks
Since 2005, each local area across the Leeds city region has had its own dedicated neighbourhood network, which operates as a form of community-based peer support. Through the networks and their many volunteers, local older people and their families get help from others in the community with the everyday tasks of care, such as free or cheap transport, social activities, shopping, practical help at home, cleaning, gardening and breaks for carers. As well as helping older people, the networks help families and carers to juggle the demands of family, work and caring, delay entry into formal care, and reduce reliance on the NHS.

Each network is responsible for a particular geographical area, determined in consultation with the community, and provides services to reduce social isolation, provide opportunities for volunteering, act as a 'gateway' to advice, information and services, and promote health and wellbeing, and thereby improve the quality of life for the individual.

Many of the networks had already been around for almost 20 years when the council took the decision to establish them as neighbourhood networks. These included existing local community institutions such as charities, community groups, live-at-home schemes and faith-based institutions.

These networks have helped delaying the entry of older people into the formal care system. Despite a growing 65-plus population, the number of older people receiving homecare and taking up places in residential care homes in Leeds is falling. The number of older people receiving homecare has decreased from over 4,200 in 2010/11 to below 3,700 in 2012/13, while the number of residential care placements funded by the council has also decreased steadily, from 172,810 bed weeks in 2002/03 to 135,522 in 2012/13.

If every authority were to contain the costs of rising demand for care in this way, IPPR estimates this would result in a saving of at least £0.36 billion per year (McNeil and Hunter 2014).

6.4 Model 4: Asset-based community development

Needs-based **Acute**

Challenge addressed by this model: the need for community-based support that strengthens people's capabilities, rather than just responding to acute need.

Empowerment is partly about making public service systems responsive to people's needs – and we have seen a number of models for achieving this implemented by governments of all parties, in particular the spread of patient choice, for example. However, it is also about strengthening people's own capabilities so that they are less dependent on services and can live more independent lives.

Asset-based community development is a model that was developed in the US which builds on the assets already found in the community and mobilises individuals, associations and institutions to come together to achieve shared goals. The aim is to support people at the right time, starting with community-based resources, rather than waiting until a person ends up with acute needs when they end up accessing services, such as emergency or residential care, generally at high cost.

Case study: Asset-based community development in the Leeds neighbourhood networks

Three of the Leeds neighbourhood networks have also piloted the asset-based community development approach through the Senior Network Support (SeNS) project.

The SeNS project is designed to combat social isolation, by developing new and existing group-based activities, such as baking groups and walking clubs. A 'community connector' is:

- a local person who is passionate about their local area and a good networker
- employed to map existing social networks, identify local needs, and find and recruit local people with a desire to share their skills.

In one of the networks, for example, the community connector helped to put a local man with experience of making walking sticks in touch with other men in the local area, who had previously mentioned the lack of social activities explicitly designed for them, to create a club for those interested in learning how to make walking sticks from materials found in the local park. The connector was able to link people up, provide small amounts of cash for materials, provide a space for the club to come together, and arrange for the club to meet with the local park authorities to get permission to take sticks.

The Leeds neighbourhood networks are also piloting a service called Local Links. Inspired and set up by Ritchard Brazil of the Stamford Forum project, it works on the principle that if people come together to fund their care needs then they can more flexibly arrange vital services such as transport or help with day-to-day tasks such as shopping and cleaning, in ways which both go beyond the generic set of options they would otherwise receive, and they are likely to save money at the same time.

The network employs local support planners with detailed local knowledge, rather than council social workers, to help with this. The older person's budget is held on behalf of the individual by the local network. If the overall package of care delivers savings on what traditional council services would have cost, half of the savings are returned to the council and half are retained by the neighbourhood network. Much of the support is highly tailored to the individual (learning new hobbies, meeting up with people to talk about shared interests) and delivered by volunteers – having a large, skilled and varied volunteer workforce is vital.

At first, all services offered are additional to an existing care package. With the help of a community broker, an individual develops a complete support plan, based upon what they want from their lives, informed by resources in the community and drawing upon voluntary capacity. A proportion of the financial savings achieved through this approach will be reinvested into the neighbourhood networks through a 'social dividend'. This empowers the local community to extend the range of services provided to local people and, in time, to embed spending on social care into local communities.

Local area coordination

Local authorities in the UK – including Derby, Cumbria, Middlesbrough and most authorities in Scotland – are adopting 'local area coordination', forming partnerships with individuals, families and local communities to promote self-sufficiency and local solutions to care needs while delivering value for money. This model has long been an important part of social care for people with disabilities in Australia, and UK local authorities are now employing coordinators to help people with support needs, including older people, to make the most of, and make a difference to, their local areas.[12]

Local area coordinators (LACs) are recruited from a range of backgrounds, have close links to local neighbourhoods and operate an 'open door' policy, providing information, support, advocacy and advice to all, regardless of their support needs or their entitlements to funding. Support may involve linking people up to existing community groups, drawing on volunteer support to enable them to get out of the house, or negotiating a role for individuals to take a more active part in their community. Coordinators can also support and advise people to access and control resources or services where they are eligible.

LACs are able to achieve successful outcomes with relatively little input, arguably because of their community location, which allows for drop-in visits, local knowledge and an informal approach, without the need for complex assessment processes (Peter Fletcher Associates 2011).

In turn, this creates the potential for cost savings. The principal costs of LAC are for staffing, and each coordinator costs approximately £40,000. In the UK, Thurrock council estimates that 5 LACs plus an LAC manager would cost approximately £380,000 annually (Sitch 2013). Evaluations of LAC in Australia, Scotland and England have shown that the scheme delivers value for money, with key savings coming from diverting people away from more expensive crisis services. The evaluation of LAC in Derby showed estimated diverted costs of £800,000 within the first 12 months, while operating at 40 per cent capacity in two locations. In Australia, the cost to authorities per service user was found to be 35 per cent lower than the national average (Government of Western Australia 2003).

At present, LAC in Scotland and parts of England is grant-funded and, as such, essentially acts as an add-on to existing case management services. In Western Australia, the LAC model will form a key part of reforms to services for disabled people, replacing case management (Disability Services Commission 2013).

6.5 Model 5: Technology-enabled care plans and data ownership

Needs-based   Acute   Fragmented

Challenge this model addresses: giving patients with long-term conditions a care plan alongside the technology and data needed to manage care and make better decisions increases independence, prevents unnecessary hospital admissions and makes the patient the main decision-maker.

There is significant evidence that care planning is beneficial to the patient and the NHS. It should lead to a reduction in emergency attendances and inpatient days, improved quality of life, greater knowledge and confidence in being able to cope with condition, better use of medication, reduced costs and overall improved quality of care (Mathers et al 2011).

Care planning can be further improved when it is implemented through the application of technological advancements. Healthcare applications (such as

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12   This section is based on previous IPPR research into finding collective solutions to social care in an ageing society; see McNeil and Hunter 2014.

VitruCare discussed in the case study below) and wearable devices can now collect invaluable health data, help the patient analyse it in real time and as a result make better-informed care decisions (see PwC 2014).

Furthermore, this data – along with the concerns and comments of patients – can be made available to doctors and specialists remotely who can then intervene or support the patient if necessary via telehealth and telecare devices. These help to ensure patients feel supported while also being independent, and have a quantifiably significant impact on hospital admissions and patient mortality (Steventon and Bardsley 2012).

As part of technology-enabled care planning patients also gain control and ownership of their health records and data. This allows patients to make better decisions and to share data about their health, but also fosters a feeling of control and ownership of their health. Seventy per cent of survey respondents felt that access to their NHS medical records would be useful or very useful in the day-to-day management of their health condition(s).

We therefore recommend that in future all patients with long-term conditions in the NHS should be given access to a technology-enabled care plan and should be given ownership of their health data in the form of a patient passport. A good example of the benefits of doing this is detailed in the following case studies on VitruCare and the work of Airedale Telehealth Hub.

Case study: VitruCare and care planning

VitruCare is an app-based health management system. It helps patients collect and analyse data about their health and care including recording blood pressure, heart rate, glucose levels, and so on. Furthermore, it can also collect more socially focused data such as exercise, diet and (for those with mental health) social activity and other depression-based metrics. This data is then shared with healthcare professionals, analysed by healthcare software and reflected back to patients in ways which allow them to make informed decisions about their care.

The app is also used as a central tool in designing and managing care plans for patients with chronic conditions. Notably, the details of the patient's care plan is loaded into the app, which then guides the patient through self-care, reminds them to take medication and gives them access to reliable and accessible guidance about their condition.

This new device is in use across Bradford, Cumbria and North Yorkshire for all patients with long-term conditions. There is significant evidence that it delivers a saving for the NHS and the GP surgery of around £1.5 million for every 10,000 patients who use it by preventing emergency admissions and assisting patients to make better decisions. Indeed, VitruCare estimates that if this was used across all patients with chronic conditions, the average GP surgery would require one less doctor.

Case study: Airedale Hospital and the Telehealth Hub

Airedale Hospital's Telehealth Hub, which links to many of the patients who use VitruCare, is one of the most advanced examples of telehealth and care in the country, where more efficient and effective communication channels are being used to keep patients at home and drive empowerment.

Specialist nurse and consultant teams are located at the Telehealth Hub 24 hours a day. As well as monitoring data of vital signs, they also run video consultations for patients and carers through encrypted video links in more than 150 nursing and residential homes across the county as well as many patients based in their own homes. This allows staff to see the patient to diagnose, review and assess their conditions, intervene to prevent deterioration, judge future care needs and provide routine follow-up and outpatient services, while keeping the patient at home and away from the acute sector.

According to figures from Airedale NHS foundation trust, between April 2012 and March 2013 telehealth and care resulted in a 35 per cent reduction in hospital admissions and 53 per cent reduction in visits to A&E, leading to significant monetary savings for the NHS. Similar programmes such as the Whole System Demonstrator programme which involves 6,191 patients and 238 GP practices across three sites in Newham, Kent and Cornwall find similar results.

Patient passports

The NHS is currently trailing patient passports in eight areas of England. In the Isle of Wight, for example, the patient passport allows access to essential aspects of a person's medical records including clinical conditions, medications and allergies, blood results, investigations undertaken and health plans. The patient owns the passport and can give it to whichever healthcare professionals they choose in order to help them manage their health. The passport is useful for clinicians because it provides secure access to a patent's data, reducing the risk of errors and enabling improved tracking and monitoring.[13]

6.6 Conclusions

This chapter has set out five care models that shift power from large bureaucracies and paid professionals towards citizens and communities. If such empowering care models were adopted much more widely throughout the NHS we would have a system that focused on the social determinants of health not just the symptoms, that provided people with personalised and integrated care, that focused on capabilities not just needs, and that strengthened people's relationships with one another. Such models have demonstrated potential to do the things we say we want in health and care: better outcomes, more responsive care and lower costs. So, if they make such sense, why have they not spread throughout the system? The next chapter turns to what needs to change at the system level to achieve a shift in the model of healthcare we provide.

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13   See this edition of the 'My Life a Full Life' newsletter: http://www.iwight.com/azservices/
      documents/2813-MLAFL-Winter-newsletter-FINAL.pdf

7.
SYSTEM CHANGE

The empowering care models described in the previous chapter showed how citizens can be given greater control over their health and care in practice, and how this can produce better outcomes and help the NHS with its financial challenge. However, these innovative models of care remain at the margins of our health and care system. Too few patients and communities have benefited from them. This chapter looks at what can be done to spread these best practice models across the system.

7.1 Changing how money flows around the NHS

One obvious lever for encouraging the spread of these models is money: a significant proportion of the new money promised to the NHS should be dedicated to funding new models of care and the way money moves around the system needs to change so that healthcare providers have incentives to do things differently.

A transformation fund

Money can be a significant driver of change, especially when offered on a quid pro quo basis for the reforms set out in this paper. This was one of several drivers of improvements in care between 1997 and 2010, where funding for the NHS more than doubled while performance targets, particularly in the acute sector, ensured that services changed (Boyle 2011).

The problem going forward is that similar increases in funding are no longer possible. The NHS, which has historically required annual increases in funding of about 4 per cent, received just 0.9 per cent more per year during the last parliament (Charlesworth 2015). For this parliament the government has pledged to fill Simon Stevens' £8 billion funding gap which will relieve the pressure to some degree, but this still leaves the service requiring a £22 billion productivity improvement.

Policymakers should resist the temptation to sink the additional funding into crisis management and day-to-day running costs, and should instead invest much of it in a ring-fenced transformation fund to help deliver the reforms set out in this paper. There are four main reasons why such a fund should be created.

1. Reform should be the number one priority of the service going forward
The £8 billion funding gap set out by Simon Stevens will grow larger if the NHS doesn't increase its annual productivity gains from its historical average 1–1.5 per cent to 2–3 per cent (Roberts 2015). This is an unprecedented challenge which requires fundamental service redesign.

2. Reform costs money
Many of the reforms set out in this paper include costs over and above the running costs of the existing services. This has been recognised through the creation of a £200 million Vanguard Fund – and through commissioning for quality and innovation (CQUIN) payments[14] – however, the figures available through these channels are insufficient (Hopson 2015). Furthermore, commissioners and providers have no access to other forms of finance such as equity finance, and public dividend capital is only available to organisations in financial distress. IPPR will shortly be publishing

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14   The CQUIN payment framework enables commissioners to fund innovation, by linking a proportion of English healthcare providers' income to the achievement of local quality improvement goals.

an analysis showing how large such a transformation fund would have to be to drive the reforms discussed.

3. Existing funding channels are insufficient for these kinds of reforms
Even if existing sources of finance such as the national tariff and CQUIN payments were increased to recognise the scale of reform needed, these mechanisms would be insufficient. Reform costs are distinct in nature. Notably, many of the costs are one-time sunk costs associated with changeover, or pump-prime investment, where the savings garnered as a result of reform are not accrued in year. For example, the integration of health and social care may involve double running costs (Gilburt et al 2014) and empowerment based on technological changes will require investment in the new equipment necessary to drive them forward. This would make both tariff and CQUIN payments insufficient as they require a return within the year. Likewise, many of the investments breach the silos between different types of care: channelling funding down existing routes would re-enforce these silos rather than breaking them down.

4. It will help ensure that the best models spread
A transformation fund of this kind can also ensure that payments are linked to the delivery of specific models of service reform which demonstrate the most potential. Put differently, it will help ensure that 'a thousand flowers' (NHS 2014a) do not bloom. Indeed, the fund can have a unique role in acting as a store of institutional memory on best practice, and of making sure the best advice, guidance and support is offered to reformers, something currently missing from our health system.

Now the case for a transformation fund is well established, we turn to its specific characteristics and functionality. This is a topic which the King's Fund and Health Foundation are researching in detail at present based on past experience.[15] However, here we set out some key criteria and principles which we can establish at this stage.

First, as implied by the analysis above, the transformation fund must be of sufficient size to really catalyse the reform agenda. As such **we recommend that the new fund should house at least half of the new money – some £8 billion – promised to the NHS by the current government**.

Second, unlike the Better Care Fund, this funding must be additional to that already allocated in the NHS's core budget. This is important because although we recognise that by diverting some of the additional £8 billion of funds away from day-to-day running of the NHS, short-term performance targets may deteriorate, the Better Care Fund demonstrated that taking funds from existing budgets absolutely guarantees it (McKeon 2014). Furthermore, reallocating funds, as undertaken to furnish the Better Care Fund, causes bad feeling and resentment, not the best way of starting a reform drive.

Third, this fund should be independently administered by a board of politically neutral experts in health and care transformation. This will avoid any perception of political partiality in the allocation of funds, prevent raids on the fund during future NHS crises which has been a significant problem with past NHS funds (Edwards 2014) and potentially allow more politically sensitive reforms, including the closure of hospitals to drive preventative healthcare, to receive the green light. It would therefore be more akin to the Independent Trust Financing Facility or the King's Fund/the Nuffield Trust than the Better Care Fund or Vanguard Fund.

Fourth, the fund should have clear and transparent criteria regarding who can access funds; how much each project can access; on what basis: and for what

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15 See: http://www.kingsfund.org.uk/projects/developing-proposal-transformation-fund-sustain-future-nhs

kind of transformation. These details are the kind of questions which will be addressed by the work being undertaken by the Health Foundation and the King's Fund. However, it is clear that the fund should focus on three key parts of the transformation agenda, by administering finance through three distinct channels: integration, technology and empowerment/prevention. Meanwhile, given these themes we tentatively suggest that potentially only health and wellbeing boards are eligible to apply for funding given that they are the only organisations which cover the whole health economy and therefore cross care silos.

Fifth, while the fund should be open to local innovation – that is, this should not be an attempt to centralise power – funding should be focused on best practice reform and should be rigorously evidence-based where possible. The fund should have the remit and resources to collect, collate and promote best practice as established by the Pioneer and Vanguard sites, and push new reformers towards these models. It should, therefore, act as a store of knowledge and a mechanism through which to ensure that we have a coherent and efficient health system once the transformation has occurred. Furthermore, clear outcome targets should be set for the beneficiaries of the transformation fund to ensure that the finance is being set wisely and delivering the biggest transformation for the investment.

Finally, it is crucial that this fund is given this remit for a significant time frame. Transformation will not occur quickly and part of its value comes from its ability to circumvent the existing (short) commissioning in the NHS. We believe that it should outlast the current parliament as a minimum, and political parties should guarantee upfront that it will receive from fund replenishment in any future financial settlements. This will give providers and commissioners the confidence and ability to drive forward long-term reform.

The payment mechanism: changing how money flows around the NHS
The previous section discussed how specific pots of money – outside the main NHS budget – can be offered quid pro quo in exchange for reform at the local level. However, the amount of money available to NHS providers and commissioners through this mechanism is always going to be limited especially when compared to the amount of money these commissioners and providers receive through existing channels. To really drive reform across the service this wider pot of money must be transferred to providers and commissioners in a way which encourages rather than stifles empowerment and wider service reform.

How providers are paid in the NHS
There are broadly four different mechanisms by which the transfer of money from commissioner to provider can occur.
- Block budget: A prospective lump-sum payment is made at regular intervals to the provider for all healthcare services, independent of the number of patients treated and the amount or quality of activity undertaken.
- Capitation-based payments: Prospective lump-sum payments are made to a provider or a network of providers per enrolled patient, for a range of bundled, specified services.
- Case-based payments: Providers are paid a fixed sum for an episode of care, based on groupings of clinically similar diagnoses or procedures that entail similar costs. This method involves less bundling than capitation payments, as reimbursement is for an episode of care, rather than a period which may or may not include activity.
- Fee-for-service: Payment is made retrospectively to providers for each unit of service provided, in other words, each activity or patient contact, according to a fixed price schedule.

The way providers are paid is a major barrier to the spread of the kind of models we have described in this paper.

Across the service the majority of providers have moved from receiving payments via block budgets – meaning a lump-sum payment made to the provider independent of the number of patients treated and the amount or quality of activity undertaken – towards payment by results (PbR) (Appelby et al 2012). PbR is a form of case-based system where providers are paid a set price, known as a tariff, for each unit of care provided. This already dominates the acute sector and is being spread into community care, mental health and even some areas of primary care.

However, the shift towards PbR is just one example of the many incentive-based changes made to the payment system: an alphabet soup of payment by performance reforms – where extra payments are made to providers who provide services via specific processes or in a specific location – have also been introduced ranging from the quality outcomes framework (QOF) in primary care, to best practice tariffs (BPTs) and CQUIN payments across the board.[16]

The increase in PbR and process-based incentive payments has had some notable benefits: primarily it has been key in cost control and driving efficiency savings (Farrar et al 2007, 2009, 2010). However, it has several key disadvantages.

- There is no evidence that it has led to increases in the quality of healthcare outcomes delivered by the service (Charlesworth et al 2014; Farrar et al 2007, 2010) and ultimately it is the outcomes and not the processes that matter to patients.
- It makes engaging in shared decision-making and offering alternative prescriptions (social prescriptions) difficult because providers only get paid for prescribing those things included in the tariff set by central government. That is, it centralises rather than devolves decision-making power and therefore keeps power away from the patient.
- It makes the kinds of reform discussed in the previous chapter such as integration and the adoption of new technologies very difficult because money is paid from different budgets in silos (primary care, acute care, community, mental health, and so on). Furthermore, the amount paid is only for each individual episode of care provided, which makes accruing enough money to make the necessary pump prime investments difficult.

There are a range of things that policymakers can do to correct these problems. We articulate two of the most significant: (i) personal budgets and (ii) payment by outcomes.

Personal budgets
One of the best ways of empowering citizens is to give them control of the money spent on their care. Personal budgets are a radical innovation because they challenge the old model of taxpayer-funded public services. Currently the public pay taxes into a collective pot and experts and policymakers at the centre of government decide how that should be spent to meet people's needs. In a system of personal budgets taxpayers would pay into a collective pot, redistributed according to need in a free at the point of use system, but then they would each be able to access it individually or indeed collectively to shape the care that they want.

Personal budgets have a number of advantages.
- They have the potential to shift power in the system fundamentally away from the large organisations that commission and provide because they give citizens the funds to deploy as they wish (subject to a clinical sign off), considerably enhancing their personal autonomy and independence.

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16   For more details see Charlesworth et al 2014.

- They should help develop a system that better aligns supply with demand: by giving the commissioning power to the citizen, we are more likely to see the shift towards more community-based and less clinical care that most experts have long called for.
- They may result in a more effective allocation of resources: even though cost savings are hard to quantify from the rollout so far, there is good evidence that they have improved wellbeing and satisfaction for at least the same cost as the old system. Moreover, the larger the budget and the better the process explained through processes of shared decision-making, the better the outcomes.

Research on the impact of personal budgets in social care has shown the following.
- The majority of those with personal budgets report more positive outcomes and wellbeing compared to when they did not have a personal budget. Those with direct payments and individual service funds report better outcomes and wellbeing than those with budgets managed by the council (TLAP 2013).
- Personal budgets have most impact when the person with the budget knows how much they have to spend and there is a wide range of options which could be purchased (Fox 2014 and Forder et al 2012). We explore how more can be done to maximise the potential of personal budgets later in this paper.

After 2009 the Department of Health piloted personal health budgets across 70 primary care trusts covering a range of chronic conditions including COPD, diabetes, long-term neurological conditions, mental health and stroke, and those in receipt of NHS continuing care, maternity care and end-of-life care. The budgets did not include the cost of seeing a GP, pharmaceutical costs or emergency care costs. There is a clinical sign off to ensure that what is proposed meets a person's agreed health and wellbeing goals.

The evaluation of these pilots found that:
- personal health budgets had a significant impact on care-related quality of life and psychological wellbeing
- they had no effect on clinical outcomes or mortality rates
- the impact was greater where the amount of money available was explained, and there was greater flexibility around how it could be spent and how it was managed
- larger budgets had more positive effects
- there was little difference in overall costs between the personal budget group and the control group, although personal budgets did have lower indirect costs associated with reduced inpatient care
- personal budget holders secured more services from outside the NHS than the control group, with budget holders more likely to purchase wellbeing and specialist health services that are often provided outside the NHS and less likely to use hospital care (Forder et al 2012: 168–170).

The evaluation concluded that personal health budgets were cost effective and supported a wider rollout. From April 2014 all those in receipt of NHS continuing healthcare funding have had the right to request a personal health budget. The NHS Five Year Forward View commits the health service to expanding what it now calls 'integrated personal commissioning', starting with patients who have long-term conditions and who also have a personal budget for social care (NHS 2014a).

We believe that to pivot the system towards the kind of empowering models of care set out in this paper we need to accelerate this process. Only by putting greater financial control directly in citizen's hands can we decisively and irreversibly shift power and control away from clinical commissioning groups (CCGs) and trusts, and push it towards the citizen and their communities. The government has said that

in the long term it wants to introduce a right to a personal budget to all who would benefit. We recommend that by 2020 any patient with a long-term condition should have an entitlement to a personal budget if they want one. Hundreds of thousands of patients controlling their own funding in this way, spending it outside traditional medical services in many cases, will be a powerful enabler of change in our model of healthcare.

Payment by outcomes and capitation
The second major payment reform needed is a move towards outcomes-based capitated budgets where outcomes can be defined as 'the results people care about most when seeking treatment, including functional improvement and the ability to live normal, productive lives' (ICHOM 2014).

These outcomes should be set through a process of coproduction involving practitioners, commissioners and most importantly patients and the public. Patients included in this process should be determined by effective segmentation of the patient population into groups with similar healthcare needs (either by frailty index or disease pathway) (Corrigan et al 2014).

This has been recognised as a long-term aim in Monitor and NHS England's 2014 paper Reforming the payment system for NHS services: supporting the Five Year Forward View, but as yet there has been little significant moves in this direction. CCGs in Barnet, Croydon, Camden, Enfield, Haringey, Herefordshire, Islington, Milton Keynes, Northumberland, Oxfordshire and Sheffield have all begun experimenting with payment by outcomes (PbO), supported by commissioning for outcome-based incentivised contracts (COBIC) and outcomes-based healthcare (OBH). Indeed, in several cases these pioneers – notably Milton Keynes – are already delivering results and clearly demonstrating the benefits of PbO in terms of patient empowerment (see COBIC case study).

Case study: COBIC in Milton Keynes
COBIC is one of just three organisations in England developing the PbO agenda through COBIC contracts.

The first COBIC contract was created in April 2011 when Milton Keynes PCT developed and used the COBIC approach to retender its substance misuse service. The previous system had been contracted on a PbR basis despite the fact that in many cases there was little link between inputs and outcomes. Paying providers for activity also created disincentives for them to be innovative in the care they provided as well as protecting siloed service provision.

The chief executive and director of strategy organised a range of engagements and events involving patients, clinicians and commissioners to determine, in an ideal world, what outcomes the service would deliver. This is a clear example of co-design and production which clearly demonstrates the benefit of PbO in terms of patient empowerment.

Having determined the outcomes that patients wanted the NHS to achieve, they gave notice on the existing contracts and issued a much more outcome-orientated contract, giving providers the freedom to innovate in service delivery in order to achieve them. The contract was ultimately given to a third sector provider and 'the service transformed in weeks, providing measurably better quality and experiences than before' with care services joining up around the patient and aiming to deliver the outcomes that they wanted most. It led to a 25 per cent saving in the cost of provision.

To shift the wider incentive structure towards the needs and requirements of patients, CCGs should move towards a form of payment by outcomes for most of the care they commission.

This would be facilitated by the following five steps.

1. The Integration and Vanguard pilots should be encouraged to implement PbO. These pioneers should be treated as a learning exercise and we should set out specific questions we would like these pioneers to answer covering the nature of best practice, the main barriers to OBH and any potential solutions.

2. NHS England and Monitor should set up a joint PbO unit. This unit would have responsibility for supporting the pioneer projects in implementing best practice and overcoming the barriers locally: essentially it would provide the service both COBIC and OBH are providing but throughout the NHS. It would also act as a store of knowledge, learning the lessons from the pioneer projects and leading the long term strategic plan for spreading PbO across the NHS.

3. A national commissioning outcome database should be established to support local areas, linked to the outcomes framework and based on best practice established in those pioneering PbO. This could be set up in partnership with COBIC, OBH and ICHOM (the International Consortium for Health Outcomes Measurement) who have already started working on such a database.

4. Patient reported outcomes measures (PROMs) should cover all of the main chronic diseases as well as acute procedures. This is challenging, but not impossible to deliver and should be prioritised.

5. Monitor, NHS England and the Health and Social Care Information Centre should set out a comprehensive data strategy for the NHS giving clear guidance and targets as to what data CCGs and providers should be collecting to facilitate payment by outcomes.

7.2 Devolving power
Enabling the spread of new models of care will require a power shift at three levels:

- to local places – to enable the shift into empowering people in the community and shifting the locus out of hospitals and into the community

- to frontline healthcare professionals – providing them with the autonomy and flexibility to design care jointly with the citizen

- to patients directly – as with personal budgets.

We have already called for an acceleration of the expansion of personal health budgets. We now turn to setting out the case for devolving more power to local areas and to the frontline healthcare workforce.

'Devo Health'
The National Health Service has historically been significantly centralised. This is perhaps unsurprising given that it was born out of the ashes of the second world war, which saw an increase in the role of central government across the whole of the UK economy.

However, it is now all too clear that devolution of power and money – or in this case decentralisation – is an idea whose time has come. The recent Scottish referendum – and the promise of 'devo max' following its conclusion – has provoked significant discussion about devolution within England. Health and social care is not immune from these developments.

Some warn against this shift. They argue that it will open the NHS up to poor local management, and expose patients to a postcode lottery. However, this argument doesn't really stack up:

- the postcode lottery in the UK already exists in that we have devolved regions such as Northern Ireland, Scotland and Wales

- this experiment (devolution to the Northern Ireland, Scotland and Wales) has seemingly had little impact on the *relative* difference in amenable mortality and

healthcare outcomes between the devolved regions despite different funding settlements (see Bevan et al 2014).

This suggests that the arguments of the detractors are ill-founded. However, neither is it a strong case for those arguing the converse: that devolution will necessarily lead to a transformation in care at the local level. Indeed, the evidence from devolution to Northern Ireland, Scotland and Wales is that devolution, even combined with increases in funding, had limited impact on healthcare outcomes.

That said, we would argue, as have others that this lack of improvement was largely down to a lack of reform in the way in which healthcare was delivered (see Warner and O'Sullivan 2015). We therefore believe that devolution can lead to efficiency savings and improved outcomes *if it is used as a driver of reform*. This is something that can, and is being tested out in Greater Manchester following George Osborne's announcement in February that Greater Manchester would get its own combined health and social care budget.

'Devo-Manc'

In February 2015 George Osborne announced that Westminster would devolve control of the Greater Manchester's £6 billion health and social care spend from April 2016.

Responsibility for this new budget will rest with a new Greater Manchester joint commissioning board, with the actual commissioning delegated to the most effective level, under the principle of subsidiarity.

However, this is about more than bringing power closer to home; it is also about driving reform and efficiency savings. Greater Manchester is forecast to have an annual budgetary shortfall for health and social care of £1.075 billion by 2017–18, its share of England's £30 billion deficit by the end of the decade (ibid). Devolution will help plug this gap by aligning all the levers for improving health at the local level.

This will be key to helping drive forward the integration of health and social care, a major part of the reform programme set out by the NHS Five Year Forward View. It will also enable greater population planning. Notably, the region will target 600,000 of the city's 3 million people who are considered most at risk of disease progression and hospitalisation. This group will be offered a special personalised care package, with the goal of eliminating at least 60,000 hospital admissions per year. These reforms, catalysed by devolution, are forecast to save around £250 million (ibid).

Going forward we recommend that 'Devo Manc' is carefully evaluated to establish whether the reform agenda set out is actually delivered, and does result in budgetary savings while maintaining (or even improving) the quality of and access to care. However, in principle we recommend the creation and expansion of a 'Devo Health' programme. More specifically we argue that the government should develop the 'devolution on demand' policy which was fleetingly set out in *The Implications of Devolution for England* (UK Government 2014). This said that in cases where there is 'genuine demand underpinned by popular support' regions could ask central government for further devolution. It added that: 'There would be a presumption in favour of devolution but checks in place would aim to ensure powers were not granted inappropriately. This system could include giving local authorities more autonomy managing their budgets.'

And demand is there: the 10 core cities – Birmingham, Bristol, Liverpool, Leeds, Manchester, Newcastle, Nottingham and Sheffield, Cardiff and Glasgow – recently published *A Modern Charter for Local Freedom*[17] which set out an ambitious devolution agenda including health and social care. This document also recommended the creation of an independent body to receive proposals for the

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17   See: http://www.corecities.com/what-we-do/publications/modern-charter-local-freedom

transfer of freedoms from the centre to local people based on publicly available criteria, and to oversee that transfer. IPPR argues that such a body should be created for the NHS which would be responsible for:

- evaluating and learning the lessons from 'Devo Manc'
- setting out what values, principles and basic minimums must be retained in the NHS across devolved regions
- setting out a criteria for green-lighting further devolution
- receiving and reviewing applications from city regions wanting further devolved powers.

However, we would expect – indeed hope – that devolution settlements would be agreed for most if not all of the 10 core cities by the end of the next parliament.

Frontline autonomy
Empowering models of care rely upon the ability of professionals to use their discretion and adapt the care provided according to the objectives of the person in receipt of that care. This requires a range of flexibility at the frontline that is lacking in many parts of our health and care system: for example, public attention has recently focused on the problems of homecare workers being limited to 15-minute visits to carry out prescribed tasks, when what the person in receipt of care wants is an ongoing, less time-constrained and deeper relationship (see Muir and Parker 2014).

Frederick Laloux argues that this kind of more autonomous frontline is optimised by certain forms of organisational design (Laloux 2014). Organisations which allow workers this space for innovation and professional judgement are likely to have flatter hierarchies, with higher levels of trust and self-management. Staff are likely to be held together and motivated by a sense of intrinsic purpose, rather than extrinsic financial incentives. They will be characterised by innovation and incremental improvement, with workers not waiting for evidence, but rather developing workable solutions, evaluating them and learning from experience.

These ideas have been applied in practice with impressive results in the Netherlands, where two-thirds of community nursing is carried out by Buurtzorg. Nurses are empowered by Buurtzorg to deliver all of the care people need in the home, with locality-based patches and technology-enabling real-time data collection. This means low levels of supervision and administration from the central team, which in turn means higher costs per hour, but a reduction in the total number of hours. This has helped to achieve a 40 per cent cost saving in the Netherlands (De Blok 2013).

7.3 Equipping the healthcare workforce to support empowering models of care

We need not just reforms to finance and devolution of power, but also a very differently configured workforce capable of delivering new models of care and possessing a very different mindset and culture to that of the traditional medical professions.

New roles and skills
The new models of care set out in this paper and in the Five Year Forward View require changes in the healthcare workforce, with a different set of skills, organised around new kinds of roles. To tackle this Health Education England (HEE) will need to think strategically and work with providers to anticipate future trends. The NHS at different levels, working with universities and colleges in particular, will need to put in place the capacity to commission new roles, recruit into those roles, retrain existing workers, and introduce new education and training programmes (see NHS HEE 2015).

Supply and demand are out of sync in the healthcare labour market. With the growth of multiple morbidity and the need to provide people who have complex

health problems with a single point of access and navigation through the service landscape, we are likely to require more community-based generalist roles. But it is exactly in this space that there is a growing recruitment crisis: the BBC recently undertook a survey of GPs and found that 56 per cent expect to retire before the age of 60 (BBC News 2015). Figures show that almost one in 10 posts for GP partners are now unfilled, a figure which has quadrupled in just four years (Donnelly 2015). Research by the Royal College of General Practitioners shows that England will need 8,000 new full-time equivalent GPs by 2020. However, nationally only 20 per cent of medical students are choosing general practice, compared to a 50 per cent target (RCGP 2015).

To address this requires a profound rethink of general practice. In order to meet growing demand we are likely to require more support staff, who are likely to be quicker to train than new GPs. Practice teams will require more nurses and physician associates who have undergone vocational training in community-based settings and with skills that will complement those of the GP, such as prescribing and advanced nursing skills. These staff could take on roles such as visiting nursing homes and people with long-term conditions in their own homes.

We will also require more specialists in areas like paediatrics who can be deployed and are trained to work in community-based settings as part of integrated general practice teams.

In order to tackle the social determinants of illness while providing support for people to avoid illness and manage their conditions effectively we are likely to require more advocacy workers and care coordinators. These could be in the form, for example, of estate or neighbourhood-based local area coordinators. Or, as we saw with Age UK's care coordinators in Cornwall, they could be based in GP surgeries. These roles are likely to require less specialist expertise and more crosscutting skills and competencies such as empathy, communication skills, a knowledge of the social causes of ill health and an ability to work across professional and service boundaries.

It is worth noting that these may not in most cases be 'new jobs', but may involve retraining existing staff to take on a wider role. These coordination roles could for example be a progression opportunity for the large healthcare support workforce. According to HEE these band 1–4 roles make up approximately 40 per cent of the non-medical workforce and provide up to 60 per cent of direct patient contact, and yet traditionally receive very little investment in their training and development (NHS HEE 2015).

Culture

The agenda described in this paper requires a profound change in professional mindsets and cultures, particularly so that we can:

- shift from a paternalistic to a coproductive model of care
- shift from a medical mindset to one that gives much greater recognition to the social determinants of illness.

It cannot be underestimated how profound a challenge this is and it is an area in which relatively little progress has been made in recent years. Medical mindsets are deeply embedded, underpinned by clinicians' understanding of their role that has emerged over centuries of medical practice. Changing this will require the following measures (Nesta 2013b and Ahmad et al 2014):

- practical decision-making tools that will help to guide GPs and specialists through the processes of shared decision-making that are at the heart of coproduced consultations
- training for new and existing professionals, for example in how to conduct proper care planning that starts with the patient's wider objectives rather than simply clinical aims

- leadership right from the top of trusts and GP practices
- senior clinical champions who will push the agenda among medical colleagues
- a core project team that provides training and support for new care models, in recognition of the fact that it will require a constant push so that professionals get used to new ways of working and do not 'default back'
- awareness of wider community programmes and initiatives that can facilitate self-management, probably best embedded in a proper referral system as with the Newcastle social prescribing model described in the case study above.

7.4 An adoption and diffusion mechanism for new innovations

Technology is key to handing people greater control over their health and care, but the NHS has a relatively poor record of adopting and diffusing innovative technologies. We need an efficient and effective method of dispersing new technologies such as care planning apps, wearable devices and telehealth and care equipment across the system (Quilter-Pinner and Muir 2015).

Adoption and diffusion of new innovations: performance so far

There is evidence that the UK will have to improve its ability to adopt and diffuse new innovations if it is to reap the benefits of technological advancement. The evidence on this is significantly stronger for drugs[18] than for non-drugs, however there is enough anecdotal evidence to imply that this applies to devices and digital technologies as well.

For example, in its key report on innovation in healthcare, *Innovation, Health and Wealth*, the Department of Health concluded:

> *'Whilst we are good at inventing and developing new technologies, the spread of those inventions within the NHS has often been too slow, and sometimes even the best of them fail to achieve widespread use.'*
> DH NHSIE 2011

Meanwhile, in a recent report on patient empowerment NHS England backed this statement up for the types of technologies discussed in this paper:

> *'59 per cent of all UK citizens have a smartphone, 84 per cent of adults use the internet. However, when asked, only 2 per cent of the population report any digitally enabled transaction with the NHS.'*
> NHS 2014b

IPPR's paper Improved circulation: Unleashing innovation across the NHS (Quilter-Pinner and Muir 2015) detailed numerous case studies of innovators who were struggling to achieve dispersion of their product, including VitruCare (see the best practice case study above).

Our research suggests that there are three main barriers to the adoption and diffusion of new technologies across the service that need addressing in looking to drive forward the care planning, technology and data model of empowerment.

Search frictions: how to bring buyers and innovators together
Innovators and buyers within the NHS often have difficulty locating each other. This is a classic example of a search friction, or asymmetric information. There are two main elements to this asymmetry.

On the seller's side the main problem is the size and complexity of the NHS. The NHS is not one entity but thousands of individual organisations, all of which

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18   For example, the Richards report (2010) compares the level of uptake for key best practice drugs in the UK and 13 other countries, and found that the UK ranked just eighth overall.

are potential consumers: NHS England, Public Health England, 211 CCGs, 168 acute trusts, nearly 11,000 GP surgeries and thousands of community providers. Locating the right organisation and individuals within it to complete a transaction is challenging. To address this we recommend that academic health science networks (AHSNs) take on a 'market matching' role, grouping together to channel innovators more efficiently into the right people within the NHS: this can be achieved by expanding services such as Innovation Connect and the Innovation Nexus.

On the buyer's side this information asymmetry surrounds knowledge about the quality and characteristics of a particular innovation. The size of the asymmetry in the healthcare market is particularly large because the issues are highly technical and specialised, and because many products are unusually expensive to purchase. Furthermore, there is another complication for many of the empowerment products discussed in this paper: notably there is limited clear evidence (for instance double blind trials) about their benefits because they are not always appropriate for these evidence collection methods. In looking to address this problem we think that the National Institute for Health and Care Excellence (NICE) should be asked to set out best practice guidance for technology-enabled patient empowerment, building on the results of the Whole System Demonstrator.[19] This would recommend the range of technologies necessary to deliver this model of care.

The principal–agent problem: how to ensure the NHS seeks out innovation
There is a lack of systematic demand for innovation from within NHS organisations; or put more simply, NHS organisations are not looking for new innovations. This, we have argued, is a result of the principal–agent problem – that is, NHS commissioners and providers being imperfect agents for the patient and failing to be innovative enough in the healthcare they deliver.

One reason for this, we argue, is because of the accountability mechanism to which they are subject, which may well lead them to prioritise balancing the budget or minimising risk rather than innovating. The challenge going forward is therefore to increase the perceived risk that providers and healthcare workers attach to a lack of innovation. One way of doing this is by recruiting 'innovation scouts' to identify areas where innovation is needed, search out best practice innovations to fill these gaps, and help to bring down barriers to adoption and diffusion. This would ensure that there are people in the NHS who are responsible and held accountable for supporting innovation, and move the service towards a so-called 'ambidextrous' organisation model.[20]

Another reason behind the principal-agent problem is an information asymmetry between commissioners and patients. This information gap works on two levels: first, the patient–clinician gap occurs because the patient–clinician relationship has traditionally been a paternalistic one, with the former a passive recipient and the latter an active specialist. Second, this kind of information asymmetry also exists in the gap between the patient–clinician and the commissioner – that is, between care and procurement. The solution to this problem is patient empowerment itself, particularly the spread of personal budgets as discussed above, and the coproduction of care pathways during integration and service redesign initiatives.

Misaligned incentives: how to allow money to flow around the NHS
The third major barrier to the adoption and diffusion of new technologies is the payment mechanism – meaning the way in which money is transferred from central government to local providers, which acts as a disincentive to innovation. Much of this ground is covered in the section on the payment mechanism above, but we will summarise briefly once again.

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19   See: http://www.nuffieldtrust.org.uk/our-work/projects/impact-telehealth-and-telecare-evaluation-whole-system-demonstrator-project
20   For more on the concept of an ambidextrous organisation see O'Reilly and Tushman 2004.

One of the primary problems with the current system is that it incentivises outputs rather than outcomes (for example a hip replacement rather than the ability to walk). As a result, innovations which achieve better outcomes while also increasing efficiency (reducing healthcare activity) are disincentivised because they reduce the income of the healthcare provider. Our paper Improved circulation highlights several examples of this problem. The solution here is to move towards a system where it is the outcomes themselves that are incentivised. This is discussed in detail earlier in this chapter.

The second aspect of the payment system problem is that it reflects and reinforces the fragmentation that already exists in healthcare provision. Any innovations that seek to move care between these silos – and so call for money to move between silos – are disincentivised or inhibited. The long-term solution to this problem lies in the integration of health and social care with pooled and capitated budgets. In the shorter term, AHSNs and Monitor should look to promote the use of 'short-term patches'. One of these is the shared savings formula, which sees the savings made by introducing an innovation in one place shared equally by the CCG and provider, or by multiple providers across the health and care system (for example, by a hospital and primary care provider). Another is the flexible tariff or local variation, which allows local CCGs to adjust the standard tariff (set centrally) if the treatment provided by the care provider differs from the standard treatment.

The final key aspect of the payment system problem is that of intertemporal disincentives, which occur when the cost of an innovation must be met upfront yet the savings are accrued at some indefinite point in the future. A main component of this problem is the short commissioning cycle operated in the NHS and the paucity of national investment funds. This problem would be partly negated by the proposal included above to create a transformation fund that would provide funding for technological transformation; other solutions include moving to a longer commissioning cycle and removing the obligation on CCGs to balance their books in cases where deficits are offset against savings at a later date. Finally, AHSNs have a key role in sourcing alternative financing mechanisms including social financing where possible.

7.5 Responsibilities of citizens and wider society

Giving citizens greater control cannot simply be a case of the state handing over power. Citizens themselves will need to take more responsibility for their own health – and, indeed, in some cases for the health of others.

The question of our personal responsibility for our own health is the subject of longstanding debate in medical ethics, covering questions which we do not have the space to address here. Nevertheless, here we briefly set out the contours of that philosophical debate, before elucidating what will be required of citizens if we are to get the most from the models of care set out in this paper.

Unhealthy behaviours: whose responsibility?

The shift in the global burden of disease towards illnesses caused in part or largely by lifestyle factors has put the question of personal responsibility at the centre of public debate. The Global Burden of Disease study shows that poor diet, lack of exercise, smoking, high blood pressure and excessive alcohol consumption are a major cause of illness and disability in the UK. International studies also confirm that healthcare only contributes 10 per cent to preventing premature death, whereas personal behaviour contributes 40 per cent (PHE 2014).

It is clearly the case that we all make choices that affect our health and that we all carry some degree of personal responsibility for these choices. We choose whether or not to buy another drink, to eat takeaway foods or to put cigarettes to our lips. However, it is also true that our choices are not always informed,

voluntary, uncoerced or deliberated. Lifestyle behaviours are often partly determined by cultural factors, health literacy, health inequalities, genetic predispositions and, in the case of smoking and alcohol, addictions. Given the complexity of the determinants of lifestyle choices it is hard to make judgments as to where personal responsibility lies, particularly at the level of public policy and particularly without knowledge of an individual patient's circumstances.

It is also true that we as a society bear some responsibility for ensuring that people live in conditions in which healthy choices are possible. At the national level this can be brought about through the state putting in place public policies which tackle the social causes of ill health and unhealthy behaviours. It can mean the state banning certain activities, which are deemed to contribute to poor health. It can also mean the state deploying the insights of behavioural sciences to encourage healthy behaviour, as we have seen with 'nudge'-style thinking.

Non-state actors also have responsibilities. For example, companies producing foodstuffs that contain too many calories or too much sugar could help by reducing the energy intensity of these foods or by signing up to more transparent labelling. Employers more widely have a responsibility for promoting healthy lifestyles among their employees. The link between health and work is increasingly well understood: good-quality work promotes better health, and a healthier workforce is a more productive one.

The citizen's responsibilities

Clearly we all have a responsibility in a collectively funded health system – in which care is always rationed to a greater or lesser extent – to take care of our own health. Our failure to do so imposes very real costs on others. But what happens if we do not? Is there some kind of feasible sanction in such cases? Some have argued, for example, that smokers should be charged for treatment where they have a recurring problem and have refused to quit smoking. However, because of the difficulty of fairly adjudicating where personal responsibility lies and because free healthcare at the point of use achieves greater equality of healthcare utilisation, charging patients for treatment in such cases is likely to produce more problems than it solves.

It is better to increase the disincentives to engage in unhealthy behaviours at the point of consumption, for example by increasing taxes on 'bads' such as alcohol. This both provides a disincentive and helps pay for the costs of illnesses related to such unhealthy consumption.

Taxing alcohol

Across the UK there are around 1.2 million alcohol-related hospital admissions per year. Alcohol-related harm costs society £21 billion annually (Home Secretary 2012). Alcohol excise taxes and value added tax (VAT) together make up over half of the price of most alcoholic drinks sold off-trade (alcohol purchased in supermarkets and off-licences) (Griffith et al 2013). However, the current system of excise taxes does a poor job of targeting heavy drinkers who are the primary problem in terms of health. However, the evidence suggests that those who drink heavily tend to purchase stronger alcohol (ibid). This provides us with a mechanism to target taxation more effectively.

We therefore support the proposals made by the Institute of Fiscal Studies (IFS) for a new tax schedule which increases the rate of tax for stronger alcoholic products. The IFS suggests that such a new tax schedule could start at 20p per alcohol unit for wines and spirits of 1 per cent alcohol by volume (ABV), and 7.1p for other alcohol. Both rates would then increase by 0.6p per unit for each 1 per cent increase in ABV (ibid). The impact of this would be to reduce purchases of alcohol in those families who buy less than seven units of alcohol a week by 2.6 per cent on average, compared to 9.5 per cent for those purchasing more than 35 units. This is therefore more effective and efficient than a minimum pricing system.

It is worth noting that the structure of alcohol excise taxes is partly restricted by an EU directive that would prohibit this reform at present (as indeed is minimum pricing as seen in Scotland).[21] One task that faces policymakers in looking to implement this, therefore, is winning support for this reform in Europe, or looking to overcome the legal challenges we might face if implemented. It is also worth noting that pricing policy can only achieve so much. It should be combined with public campaigns to warn of the health risks of alcohol and challenge the binge-drinking culture which has developed.

In addition we should expect citizens to act in ways that support the new models of care set out in this paper. This might include the following.

1. First, citizens will need to be fully involved in consultations and care planning. They will need to be better informed about their conditions and how to manage them. To do this they may need to attend courses, as with the expert patient programme, and get involved in peer support groups.

2. Second, citizens will need to take up the support that is offered. For example, they will need to comply with social prescriptions that are agreed with the doctor, such as therapies or gym memberships. They will need to work actively to achieve the goals agreed in the care plan. If they do not do this then these models of care will not be effective and will have to be withdrawn.

3. Third, citizens will have to share more of their personal data with different public services to achieve the kind of integrated care set out in this paper. For example, they may have to respond to prompts put forward by different agencies or set defaults to allow professionals to access their medical and care records.

4. Fourth, citizens will need to be more involved in community organisations and networks of people who support each other. If we are to respond to the epidemic of mental illness, for example, all of us will have to play a more active role in looking out for each other and supporting people at risk of loneliness or isolation.

5. Fifth, where they are able, citizens will have to purchase and utilise new technologies such as mobile devices, smartphones and wearable tech that will help them monitor their vital signs and communicate these to their GP or specialist.

7.6 Conclusion

In this chapter we have argued that five systemic steps are required to help empowering models of care to spread: we need a transformation fund to resource these new models; we need personal budgets and payment by outcomes to incentivise change financially; we need to equip the healthcare workforce with new skills and roles; we need to improve the adoption and diffusion of new technologies; and we need citizens to change their behaviours and to take up new responsibilities.

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21 See European Commission Council Directive 92/83/EEC: http://eurlex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:31992L0083:en:HTML

8.
CONCLUSIONS AND SUMMARY OF RECOMMENDATIONS

The NHS is one of the most effective healthcare systems in the world, in particular when it comes to equality of access, equity of healthcare utilisation, cost control and public confidence. Nevertheless it is currently under significant pressure as a result of financial constraint, an ageing society and the changing nature of disease.

In the long term we need to change our model of healthcare to one that is tri-focused on preventing disease, on the self-management of conditions by citizens themselves, and on accessible care provided in the community.

What will enable this shift? It will require five things. First, **resources will need to move out of acute care and into health creation**. Second, **services need to become more integrated**. Third, **the health workforce will need to change to provide these new models of care**. Fourth, **the system will need to adopt and diffuse new technologies**. Finally, **citizens will need greater control over their health and care**.

We have argued that empowerment is a good thing in and of itself – people should have greater control over their own lives. But empowerment also produces better health outcomes, improved patient satisfaction and could save money in particular in reduced hospital admissions.

Reforms intended to empower patients have so far been inadequate. They have focused on the acute sector, seen people as individuals cut off from relationships and networks, empowered citizens in relation to individual services rather than treating them as whole people, and focused on people's needs not their capabilities.

There are promising and empowering models of care being tried out all around the country. These include: social prescribing models that address people's social, emotional and practical, as well as medical needs; brokerage and integration models that join up services around the person rather than people having to navigate a fragmented service; peer support models that mobilise the knowledge, skills and empathy of people with similar conditions so that they can better manage those conditions themselves; asset-based community development models that focus on strengthening people's capabilities so they are less dependent on services and can lead independent lives; and technology-enabled care plans that provide people with the technology and data needed to better manage their condition themselves.

Nevertheless we found that these models are at the margins of the system. What can we do to help them spread? We identified five different systemic enablers:

1. **a transformation fund** to invest in new models of care and drive change in the healthcare model provided throughout the country
2. **changes to the way money flows around the system**, such as by rolling out personal budgets for those with long-term conditions so the citizen becomes the commissioner, and by adopting payment by outcomes and capitated budgets
3. **equipping the healthcare workforce with the roles and skills required to provide these new models of care**, as well as moving to a more

coproductive culture and redesigning organisations so that they provide more autonomy to frontline professionals

4. **a better adoption and diffusion mechanism for technologies that will support these new models of care**, such that it is easier to sell products into the NHS and such that the NHS itself is demanding innovation

5. **a more active role for citizens** by being more involved in and prepared for care planning; by actively seeking to achieve the goals agreed; by sharing their health data with professionals from different service organisations; by getting involved in the community and by helping others; and by purchasing and utilising new technologies.

The NHS faces a challenge over the next decade of meeting growing and more complex demand within tight financial constraints. There are already many examples of doctors, nurses, managers, community workers and patients trying out innovative models of care that show how this challenge can be met. The task for policymakers is to ensure that we have a healthcare system that supports these empowering models and enables them to spread.

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APPENDIX
PROJECT ADVISORY BOARD

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