

Expert patients

Cathy Corrie and Amy Finch

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#expertpatients

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Cathy Corrie is a Senior Researcher at *Reform*
Amy Finch is a Researcher at *Reform*

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Executive summary

The exam question facing the NHS at the beginning of the next Parliament is to save £22 billion by 2020-21. According to the NHS England *Five Year Forward View*, savings at this level will enable the NHS to manage without a deterioration in quality or a demand for emergency funds which, in the current fiscal climate, may not be available.

The NHS should embrace patient engagement as a key means to achieve its £22 billion target. In recent years, a considerable range of evidence has shown that patient engagement can improve both outcomes and use of resources. At a time when services are stretched, helping patients to manage their own conditions can reduce demand on traditional services:

- > A review of self care commissioned by the Department of Health found effective interventions can reduce hospital admissions by as much as 50 per cent.
- > The value of informal care, provided by friends and family members, now exceeds the total NHS budget. In social care, the NAO has estimated informal care is worth £100 billion per year. That compares to local authority spending on care of around £20 billion per year.
- > Shared decision-making and patient decision aids have been proven to reduce the likelihood of invasive surgery, high cost treatments and unnecessary tests.
- > Similarly, conditions such as cancer, respiratory disease and heart disease can be targeted through smoking cessation programmes, improvements to diet and physical activity, and better information.

This report presents four case studies of successful patient engagement:

- > The Vitality programme provides incentives for healthy behaviour in South Africa, the UK and the USA. Members earn “points” for taking part in gym sessions, enrolling in smoking cessation programmes and buying healthy foods in partner supermarkets.
- > Personal health budgets, in the UK and overseas, have led to better health and wellbeing. They improved value for money due to reduced demand for hospital and GP services and better negotiation over prices with providers.
- > Introduced by Kaiser Permanente, Health Connect is an online portal which enables patients to email clinicians, view personal health information, schedule appointments and take online health assessments. Patients have reported greater confidence and success in self-management as a result.
- > PatientsLikeMe is a US-based online community which enables patients to meet others with similar conditions and share their experience. One review found that patients better adhered to medication and needed fewer visits to A&E as a result.

The NHS has launched several initiatives to improve patient engagement but the impact has so far been limited:

- > The NHS Constitution was established to drive greater patient engagement yet according to one survey, 76 per cent of patients had not heard of the Constitution before receiving treatment.
- > Only 51 per cent of patients are aware of their right to choice of NHS services.
- > Neither NHS Direct nor 111 have had the “disruptive” effect on the NHS that was hoped for. Relatively few patients use the service and high numbers are consequently referred to either a GP or A&E.

- According to a 2013 survey, 97 per cent of consumers would like access to their electronic health records yet 67 per cent remain unable to do so.

Recommendations

This report estimates that stronger patient engagement could lead to savings of nearly £2 billion by 2020-21, i.e. around 10 per cent of the NHS England target saving.

The savings would comprise more self care, improved public health, and greater patient contribution to their care, such as a diabetic measuring their own blood sugar levels.

The £2 billion saving is consistent with the findings of the last landmark government review of NHS funding. Sir Derek Wanless' review, published in 2002, also found that greater engagement would contribute to lower costs and better outcomes. (Sir Derek Wanless estimated that the NHS would spend around 2 per cent of GDP more under a "fully engaged" scenario compared to a "slow uptake" scenario, or around £30 billion per year by 2022-23. The majority of this saving would come from higher NHS productivity.)

More than a decade later, however, improvements to public health remain marginal and in some areas, such as obesity, are in decline. The NHS is now paying the price.

The involvement of private providers in the NHS is controversial for some. However creating an NHS fit for "full engagement" will require the use of outside expertise. Industries such as banking and retail have used technology to put the customer first, such as loyalty cards, and harness the consumer's own contribution to services, e.g. self-checkout. Leading NHS hospitals are already bringing in private sector expertise to improve customer service. NHS organisations, from hospitals to primary care to commissioners, should go further to bring this outside expertise into the NHS.

Innovators outside the NHS are already giving patients the opportunity to engage in their health and care. Private and third sector organisations are going direct to the consumer to offer services not typically offered by the NHS. Social networking sites such as IWantGreatCare and PatientsLikeMe give patients a forum to give feedback on services, learn from other patients and track their own conditions. Apps such as Babylon are giving patients access to "virtual" primary care. These disruptors will help the "expert patient" to emerge more quickly outside the NHS than from within.

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The price of poor engagement

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“... patient and public engagement is a key determinant of outcomes and spending.”

Rising demand and higher healthcare costs are increasingly seen as inevitable. Since 1948 spending on the NHS has grown by an average of 3 per cent each year, and the OBR has forecast that spending will continue to rise due to demographic pressure. However greater demand on existing services is not a given. As the Wanless report on healthcare funding recognised, patient and public engagement is a key determinant of outcomes and spending. There is now an international body of evidence to show that improving patient engagement in health and care could drive high value, high quality healthcare. Yet the health service has so far made little progress. Now the *Five Year Forward View* has made realising the potential of patient engagement in health and healthcare part of their strategy to close the “funding gap”.

Higher health spending

“...the *Five Year Forward View* has made realising the potential of patient engagement in health and healthcare part of their strategy to close the “funding gap”.”

Over the last 50 years healthcare spending has grown by an average of 3 per cent a year. Between 2000 and 2010 spending doubled.¹ Spending on the NHS now represents a sixth of all public expenditure and is the largest single item of expenditure after welfare. In the 2010 Spending Review the Coalition ring fenced the health budget from reductions in public spending. This was in part based on the expectation that healthcare costs would continue to grow at their historic rate of 4 per cent a year. This meant that the NHS would need to achieve productivity gains of £15-20 billion by 2014-15.

Recent forecasts have suggested that healthcare costs will continue to grow. If spending on the NHS continues to be protected in real terms, the funding gap will widen even further. In 2012 the Nuffield Trust calculated that the funding gap could reach between £28 and £34 billion by 2021-22, and in 2013 NHS England projected a £30 billion shortfall by 2020-21.² Longer term projections from the OBR suggest that healthcare spending could reach 8.5 per cent of GDP in 2063-64.³

The most recent forecasts of NHS spending have been published by NHS England in the *Five Year Forward View* which also outlined three spending scenarios. On current trend the £30 billion funding gap in 2020-21 was projected to be cut by a third to £21 billion. The most optimistic third scenario modelled efficiency gains worth 2-3 per cent net each year, closing the funding gap with the addition of funding increases as the population grows.⁴

Closing the gap

“While there have been productivity improvements in the NHS there is growing concern about whether the service is sustainable in its current form.”

While there have been productivity improvements in the NHS there is growing concern about whether the service is sustainable in its current form. The National Audit Office and the Health Select Committee have both warned that the majority of efficiencies over this Parliament have been achieved through national policies, such as reducing prices for secondary care and a national pay freeze, and not through reform to front line services.⁵ As Monitor’s quarterly reports demonstrate NHS foundation trusts have been falling behind in their cost improvement plans and now stand at 18 per cent behind that planned for 2013-14.⁶ Monitor and the Trust Development Authority have also forecast that between 40 and 50 per cent of acute hospitals could be in deficit by the end of the financial year.⁷

1 Health Select Committee (2010), *Public expenditure*.

2 Roberts, A. et al. (2012), *A decade of austerity? The funding pressures facing the NHS from 2010/11 to 2021/22*; NHS England (2013), *Call to Action*.

3 Office for Budget Responsibility (2014), *Fiscal sustainability report*.

4 NHS England (2014), *Five Year Forward View*.

5 National Audit Office (2012), *Progress in making NHS efficiency savings*; Health Select Committee (2012), *Public expenditure*.

6 Monitor (2014), *NHS foundation trusts: quarterly report (quarter 1 2014/5)*.

7 NHS Trust Development Authority (2014), *Paper D: NHS Trust Service and Financial Performance Report*, Board meeting, 20 November 2014; Monitor, (2014), *Performance of the foundation trust sector: end year 31 March 2014*.

“70 per cent of the resources of the NHS are spent on the treatment of long term conditions.”

Surveys of NHS leaders also suggest the current approach to efficiency is not sustainable, and there is growing pessimism about the financial state of the service.⁸ Consequently, many have begun to call for additional health spending to close the funding gap.

What is driving rising costs?

Projections of higher healthcare spending are based on a number of factors, such as historic trends and changes in demography and morbidity. An ageing population and the growing prevalence of chronic conditions are often cited as causing the rise in healthcare costs. However as the OECD has demonstrated, ageing only accounts for a small proportion of recent increases in public spending.⁹ Between 1995 and 2009 health spending grew by 4.3 per cent per year, with ageing accounting for 12 per cent of the increase. Similarly, the Nuffield Trust’s recent projection suggests that population ageing accounts for 40 per cent of the growth in healthcare spending up to 2021-22.¹⁰ The remaining “residual” growth is widely seen to be due to non-ageing related demand, rising prices and the cost of technology. Policy decisions and preferences are also a key factor in the long term growth healthcare costs. A study by the IMF suggests that these “residual” factors or “excess cost growth” are a larger factor in explaining historic and future growth in healthcare costs for the UK compared to other advanced economies.¹¹

“Rising demand on NHS services is not a given.”

There are a minority of high risk patients that consume the majority of health resources. These patients typically have multiple complex chronic conditions. It has been estimated that 70 per cent of the resources of the NHS are spent on the treatment of long term conditions.¹² Department of Health data suggest that patients with long term conditions account for 50 per cent of all GP appointments, 64 per cent of all outpatient appointments and 70 per cent of all inpatient bed days.¹³ A significant proportion of patients with mental health conditions also suffer from mental health problems which exacerbate total health costs by a factor of at least 45 per cent.¹⁴

The Wanless Review and public engagement

“In 2002 Sir Derek Wanless’ review of health spending projected that higher levels of public engagement could significantly improve health outcomes and reduce cost.”

Rising demand on NHS services is not a given. In 2002 Sir Derek Wanless’ review of health spending projected that higher levels of public engagement could significantly improve health outcomes and reduce cost. Wanless developed a model of health service expenditure to project three alternative scenarios by 2022: slow progress, slow uptake and fully engaged. According to these scenarios, a greater level of reform would lead to better health outcomes and lower cost. Under the fully engaged scenario where there had been the greatest reform, healthcare expenditure would have been reduced by almost 20 per cent by 2022-23.

Table 1: NHS expenditure under Wanless’ engagement scenarios

Source: Wanless, D. (2002), *Securing our future health*

	2002-03	2007-08	2012-13	2017-18	2022-23
Total health spending, % GDP					
Solid progress	7.7	9.4	10.5	10.9	11.1
Slow uptake	7.7	9.5	11	11.9	12.5
Fully engaged	7.7	9.4	10.3	10.6	10.6

8 King’s Fund (2014), *Quarterly Monitoring Report October 2014*.

9 Maisonneuve, C. and Martins, J. (2013), *Public spending on health and long term care: A new set of projections*, OECD.

10 Roberts, A. et al. (2012), *A decade of austerity? The funding pressures facing the NHS from 2010/11 to 2021/22*, Nuffield Trust.

11 IMF (2010), *Macro Fiscal Implications of Health Care Reform in Advanced and Emerging Economies*.

12 Department of Health (2012), *Long term conditions compendium of information*.

13 Ibid.

14 Naylor, C. et al. (2012), *Long-term conditions and mental health: the cost of co-morbidities*, King’s Fund.

Under Wanless' fully engaged scenario, a key component of healthcare expenditure is public behaviours; not so much how "the service responds over the next 20 years, but the way in which the public and patients do." The report described a vision of "tomorrow's patients" who would be better informed, less deferential to clinical professions and have greater control over the services they use. As well as transforming how individuals behave as patients, public engagement would lead to greater wellbeing. Public health would improve dramatically as people would have better diets, exercise more and curb smoking and drinking. Wanless set out that patients' rights should be strengthened by setting out clearly what the health service will and will not provide, while patients should "seek to use health services responsibly and ensure that their actions do not add unnecessarily to the costs of the service".¹⁵

Table 2: Summary of Wanless' engagement scenarios

Source: Wanless, D. (2002), *Securing our future health*

Scenario 1: Solid progress	People become more engaged in relation to their health. Life expectancy rises considerably, health status improves and people have confidence in the primary care system and use it more appropriately. The health service becomes more responsive, with high rates of technology uptake, extensive use of ICT and more efficient use of resources.
Scenario 2: Slow uptake	There is no change in the level of public engagement. Life expectancy rises by the smallest amount in all three scenarios. The health status of the population is constant or deteriorates. The health service is relatively unresponsive with low rates of technology uptake and low productivity.
Scenario 3: Fully engaged	Levels of public engagement in relation to their health are high. Life expectancy increases go beyond current forecasts, health status improves dramatically and people are confident in the health system, demanding high quality care. The health service is responsive with high rates of technology uptake, particularly in relation to disease prevention. Use of resources is more efficient.

"Improvements in public health and ill health among the elderly, greater self care amongst those with long term conditions, and changes in the delivery of care... to enable patient involvement are just some of the ways in which engagement and reform underpinned Wanless' projections of healthcare spending."

The behaviours of tomorrow's patient would have considerable implications for services. Improvements in public health and ill health among the elderly, greater self care amongst those with long term conditions, and changes in the delivery of care, such as through ICT and medical technology, to enable patient involvement are just some of the ways in which engagement and reform underpinned Wanless' projections of healthcare spending [see Annex 1]. The assumption was that these different public behaviours (determined by the level of "engagement") would result in different degrees of productivity. This was the key factor in determining the level of healthcare expenditure. Under the fully engaged scenario, there would be productivity improvements of between 2.5 and 3 per cent each year between 2002-03 and 2022-23.¹⁶

This varying degree of productivity, determined by public behaviour and system changes to the NHS, was the key factor responsible for the level of healthcare expenditure. System reforms included many changes separate to managing demand through "full engagement", such as meeting national service frameworks and reducing waiting times. The Wanless projection did however attribute a conservative proportion of savings to the NHS budget through managing rising demand as the population aged and became more prone to chronic illness. This was through measures including greater self management of conditions, improved population health as patients became more responsible for their health, and harnessing the contribution of patients to co-produce their care, for example through technology.

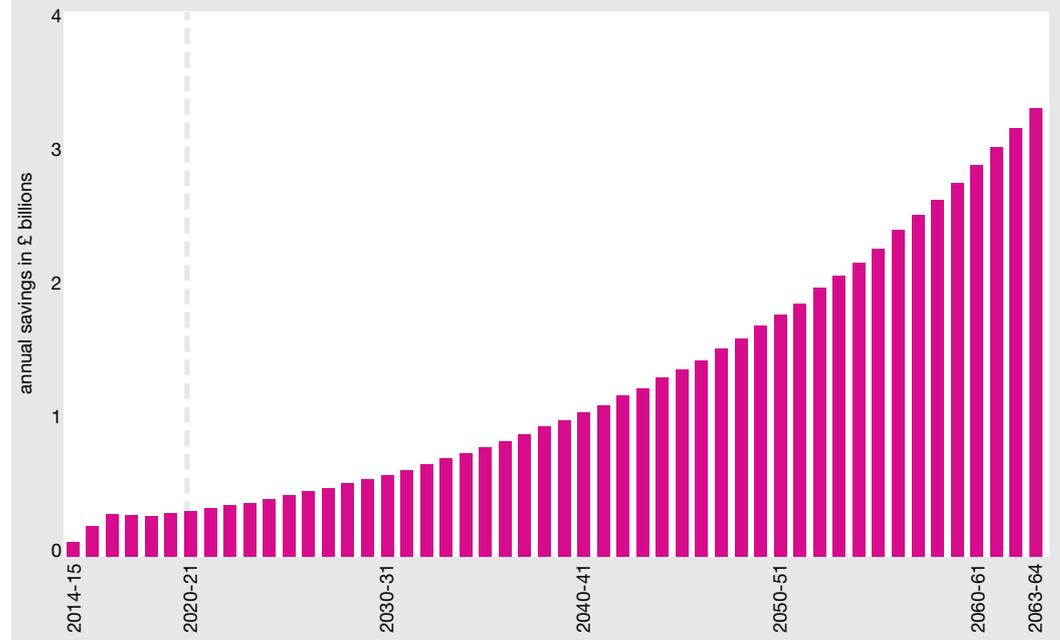
¹⁵ Wanless, D. (2002), *Securing our future health*.

¹⁶ Ibid.

Taking this assumption modelled by the Wanless Review and bringing it up to date with current forecasted spending, patient engagement could save the NHS an estimated £1.9 billion by 2020-21. This represents a recurrent annual saving of 0.3 per cent of the health budget (see Figure 1). That is almost 9 per cent of the £22 billion efficiency savings needed by NHS England by that date. By 2063-64 this could generate a cumulative saving of £62 billion.

Figure 1: Annual savings through patient engagement

Source: Wanless, D. (2002), *Securing our future health*; Appleby, J. et al. (2010), *Improving NHS productivity*, King's Fund and IFS; Office for Budget Responsibility (2014), *Economic and Fiscal Outlook*; Office for Budget Responsibility (2014), *Fiscal sustainability report*



The value of patient engagement

There is now an international body of evidence to demonstrate the benefit of patient and public engagement in health.¹⁷ As Jeremy Taylor, Chief Executive of National Voices, has explained, “Informed, engaged patients make better choices and are able to work in partnership with professionals to make better decisions and deliver better quality, better outcomes and sometimes reduced cost.”¹⁸ Managing rising cost and demand on NHS services is more important now than ever. As Simon Stevens outlined in his maiden speech as Chief Executive of the NHS, “At a time when resources are tight we are going to have to find new ways of tapping into...sources of renewable energy”, by “boosting the critical role that patients play in their own health and care.”

There are a number of ways in which patients can be involved in their health. Patient engagement can be broadly defined as a process by which patients are put at the forefront of their health and care. It is built on a partnership between individuals, families and services which enables patients to retain control of their health and make informed decisions about their care.¹⁹ Underpinning this must be an active partnership between patient and clinician, rather than the patient acting as a passive recipient of their care. There are a variety of ways in which this can be achieved, including supporting shared decision-making, supporting self care, improving understanding through health literacy and patient activation, and engaging patients to live healthier lives.

“There is now an international body of evidence to demonstrate the benefit of patient and public engagement in health.”

¹⁷ The Commonwealth Fund (2012), *International perspectives on Patient Engagement: Results from the 2011 Commonwealth Fund Survey*.

¹⁸ Jeremy Taylor to Reform conference, *A strategy to fix healthcare*, 24 January 2014.

¹⁹ National Voices (2014), *Prioritising person-centred care – the evidence*, accessed June 2014, <http://www.nationalvoices.org.uk/evidence>.

“...shared decision-making programmes and the use of decision aids reduce the likelihood of patients choosing invasive surgery, high cost treatments and unnecessary tests...”

Shared decision-making

Shared decision-making programmes encourage clinicians and patients to collaboratively select a course of action based on both clinical evidence and the patient's informed preferences.²⁰ This can be supported through decision aids to help patients better weigh the benefits and risks of a particular course of action.²¹

These interventions have been found to improve both patient satisfaction and clinical outcomes, particularly in the short term, for example through better “adherence” to treatment and medication.²² An evidence review by the Health Foundation found that shared decision-making programmes can improve patient's understanding of their condition, their self-confidence to be able to participate with their clinician in decision-making and their experience of care.²³ Moreover trials have shown that shared decision-making programmes and the use of decision aids reduce the likelihood of patients choosing invasive surgery, high cost treatments and unnecessary tests, with no adverse effect on patient satisfaction or health outcomes.²⁴

Self care

Supporting patients to self care is a vital part of the management of health conditions. This is particularly important for the 15 million people in the UK with long term conditions, 80 to 90 per cent of whose care is undertaken by themselves, friends and family. Empowering patients to take care of their health in their own homes allows people to retain control of their lives and improve their own health.²⁵ When people are supported to self manage their condition, pilots have found a number of benefits for patients and services. This includes improved patient knowledge and understanding of their condition, improved confidence, improved health behaviours and adherence to treatment recommendations.²⁶

At a time when services are stretched, helping patients to self manage their conditions can reduce demand on traditional services. A review of self care interventions commissioned by the Department of Health found that effective interventions can reduce GP visits by as much as 69 per cent, hospital admissions by as much as 50 per cent, the number of bed days by up to 80 per cent and achieving savings of 10-15 per cent.²⁷ The Expert Patient programme has had similar success. These courses taught patients to better manage their condition, costing between £200 and £400 per patient while delivering savings on average of £800.²⁸ A study of 1,000 patients on the programme found GP consultations were reduced by 7 per cent, outpatient appointments were reduced by 10 per cent and A&E attendance was down by 16 per cent over six months.²⁹ One study estimated that mobilising patients' knowledge and contribution to care through a programme of initiatives costing between £100 and £450 per person could deliver savings of £4.4 billion in the NHS.³⁰

Supporting patients with long term conditions to better manage their conditions through recommended courses of treatment could both improve patient outcomes and reduce unnecessary costs. 30 to 50 per cent of those living with long term conditions do not take treatment as recommended.³¹ Failure to adhere with recommended medication

20 Coulter et al. (2011), *Making shared decision-making a reality*, King's Fund.

21 Coulter A. and Ellins J. (2007), “Effectiveness of strategies for education, and involving patients”, *British Medical Journal*, Vol. 335, p.26.

22 Nunes, V. et al. (2009), *Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence*.

23 Health Foundation (2012), *Helping people share decision-making*.

24 O'Connor AM et al. (2007), “Toward the ‘tipping point’: decision aids and informed patient choice” *PubMed*, 26(3); Stacy et. al (2014), *Decision aids for people facing health treatment or screening decisions*, The Cochrane Collaboration, p.2.

25 Health Foundation (2011), *Helping people help themselves*.

26 National Voices (2014), *Supporting self management*.

27 Department of Health (2007), *Research evidence on the effectiveness of self care support*.

28 Bunt, L. and Harris, M (2009), *The human factor*, Nesta.

29 Expert Patient Programme Community Interest Company (2010), *Self care reduces costs and improves health – the evidence*.

30 Horne, L. et al. (2012), *People powered health: Health for people, by people and with people*, Nesta.

31 Barber, N. et al (2004), “Patients' problems with new medication for chronic conditions,” *Quality and Safety in Health Care*.

“30 to 50 per cent of those living with long term conditions do not take treatment as recommended.”

“Improving patient skills and confidence to treat minor ailments could relieve a significant burden on GP services...”

courses is the most common issue related to preventable drug related admissions.³² Avoidable medicines wastage in primary care alone costs the NHS £150 million each year.³³

For the population at large, including those without long term conditions, self care would be similarly valuable to support patients with minor conditions such as the common cold or back pain. Even of those patients who do attempt self care, a large proportion abandon self care within 4-7 days which is often premature.³⁴ Improving patient skills and confidence to treat minor ailments could relieve a significant burden on GP services, costing the NHS £2 billion each year and estimated to make up a fifth of GP appointments. One in five people visit their GP in any given year because of back pain, for example, and yet the majority of cases can be treated with over-the-counter medication and self care aids.³⁵ Similarly around 20 per cent of emergency admissions to hospital are thought to be preventable, many involving those suffering from chronic conditions.³⁶

Keeping healthy

“Lifestyle choices are a primary determinant of health.”

Lifestyle choices are a primary determinant of health. An individual's decision to curb “bad” behaviours, such as smoking and excessive drinking, and increase “good” behaviours, such as regular exercise and healthy diet, has a significant impact on mortality. Smoking, high blood pressure and obesity accounted for about 30 per cent of all years of life lost to disability in the UK in 2010.³⁷ According to one study, the likelihood of an overweight male aged 50 who smokes surviving 15 years without coronary artery disease, stroke or diabetes is 56 per cent. However if he or she was to quit smoking the probability increases to 71 per cent. Increasing activity raises the probability to 81 per cent, while losing weight raises the probability to 86 per cent.³⁸

There are a number of ways in which preventative and health promotion activities can help to counter act these “bad” behaviours and their impact on a number of diseases. Preventable illnesses place significant strain on health resources. The cost of smoking related illness for example has been estimated at £5.2 billion each year while obesity costs the NHS £5 billion and the UK economy £15.8 billion annually.³⁹ Heart disease alone costs the UK economy £29 billion each year. Cancer and circulatory disease are the most frequent causes of death in this country, many premature deaths from which are preventable. Conditions such as cancer, respiratory disease and heart disease can be effectively targeted through smoking cessation programmes, diet and physical activity programmes and better information and tools to support individuals to live healthier lives, on a targeted level or through mass media. Smoking, for example, is the greatest cause of preventable illness and early death.⁴⁰

There has therefore been growing efforts to incentivise patients to live healthier lives, to improve patient outcomes and reduce NHS expenditure in the long term. A study by NICE assessing behaviour change interventions suggested that 15 per cent of the 200 interventions assessed yielded savings and a large majority were deemed cost-effective against the criteria of £20,000 per quality-adjusted life year (QALY) gained.⁴¹

32 Howard, R. et al. (2007), “Which drugs cause preventable admissions to hospital? A systematic review,” *British Journal of Clinical Pharmacology*.

33 Royal Pharmaceutical Society (2012), *Medicines optimisation: the evidence in practice*.

34 Proprietary Association of Great Britain (2009), *Making the case for the self care of minor ailments*.

35 NHS Choices (2014), “Home remedies for common conditions”, accessed June 2014, www.nhs.uk/Livewell/Pharmacy/Pages/home-remedies-for-common-conditions.

36 Blunt, I. (2013), *Trends in emergency admissions for ambulatory care sensitive conditions, 2001 to 2013*, Nuffield Trust and Health Foundation.

37 Foot, C. et al. (2014), *People in control of their own health and care*, King's Fund.

38 C3 Collaborating for Health (2011), *Vitality Wellness Programme: Experience from South Africa*.

39 Allender et al. (2009), “The burden of smoking-related ill health in the UK”, *British Medical Journal*, Vol 18; Department of Health (2013), *News release: Reducing obesity and improving diet*, 25 March 2013; Public Health England (2014), *New release: Obesity and Health*.

40 National Voices, (2014), *Promoting prevention*.

41 Foot, C. et al (2014), *People in control of their own health and care*, King's Fund.

“Individuals with long term conditions are the most intensive users of health and care services but a lack of patient engagement means these patients make greater demands on NHS services than need be the case.”

Health literacy

Health literacy is the degree to which individuals can obtain, process and understand the basic health information and services they need to make informed health decisions.⁴² This is the pre-requisite of shared decision-making, effective self care and maintaining a healthy life. Patients with low health literacy have poorer health statuses, higher rates of hospital admission, are less likely to adhere to prescribed treatments and self care plans, experience more drug and treatment errors, and make less use of preventive services.⁴³ A review of health literacy interventions identified a positive effect on the use of health services in 9 out of 14 surveys.⁴⁴

In recent years “patient activation” programmes have sought to improve the health literacy and capability of patients. Successive studies have highlighted that these programmes have given patients the confidence and skills to self-manage, participate in decision making and make more informed choices. A major study of over 25,000 patients in the United States found that patients with higher levels of activation were less likely to attend emergency departments and more likely to proactively manage their health through seeking advice and changing behaviour faster.⁴⁵ Another study of over 5,000 patients found those with greater skills, knowledge and confidence reported far higher levels of satisfaction and in turn better experiences of care.⁴⁶ Similarly, patients that are well informed about their treatment and options are more likely to adhere to their care plan and regimen. It has been calculated that patients with lower levels of activation cost 8 to 21 per cent more than patients with the highest levels of activation.⁴⁷

The price of poor engagement

While high risk individuals are seen as the key driver of healthcare spending, there is considerable evidence to suggest that lack of patient engagement is exacerbating these costs. Individuals with long term conditions are the most intensive users of health and care services but a lack of patient engagement means these patients make greater demands on NHS services than need be the case. This can be seen in particular in the pressures made on acute services and the impact of poor disease management.

Poor disease management

Research has demonstrated that while patients with chronic illness have severe medical needs, they are often poorly engaged in managing their condition. So-called “adherence” to medication is a particular problem. Only 16 per cent of patients who are prescribed a new medicine follow their regimen as prescribed, experience no problems and receive all the information they need. Similarly, ten days after starting a medicine, a third of patients are already “non-adherent”, with over half unaware that they are not following their regimen correctly.⁴⁸

The inability for patients to manage their condition often leads to costly complications. In the case of diabetes for example, the total cost of direct patient care across the UK has been calculated at £9.8 billion in 2010-11. However “indirect costs”, such as managing complications, are significantly greater at £13.9 billion.⁴⁹ As the National Audit Office has shown, there is significant variation in the quality of care and support diabetic patients receive to manage their own condition.⁵⁰ The National Diabetes Audit found that

42 Nielsen-Bohman, L. et al. (2004), *Health literacy: A prescription to end confusion*, Institute of Medicine; Parker, R. et al. (2003), *Health literacy: a policy challenge for advancing high-quality health care*.

43 Nielsen-Bohman, L. et al. (2004), *Health literacy: A prescription to end confusion*, Institute of Medicine.

44 Agency for Healthcare Research and Quality, *Health Literacy Interventions and Outcomes: An updated systematic review*, No. 199.

45 Greene, J et al. (2012), *Why does patient activation matter*, The Commonwealth Fund.

46 Greene J. et al. (2013), “When seeing the same physician, highly activated patient have better care experience than less activated patients”, *Health Affairs*, 32(7).

47 KPMG (2014), *Creating new value with patients, carers and communities*.

48 Barber, N. et al. (2003), “Patients’ problems with new medication for chronic conditions”, *British Medical Journal*.

49 Hex, C. et al. (2012), “Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs”, *Health Economics*.

50 National Audit Office (2012), *The management of adult diabetes services in the NHS*.

“...ten days after starting a medicine, a third of patients are already “non-adherent”, with over half unaware that they are not following their regimen correctly.”

only 16 per cent of people with diabetes are achieving recommended levels of control over their blood glucose, blood pressure and cholesterol. Consequently, 84 per cent of patients are in greater danger of developing future complications. Other studies have suggested that over a third of diabetes patients have poor “adherence” to their regimen.⁵¹

Demand for acute care

Recent research has demonstrated that pressure on hospital services is driven by a small number of patients, and that a significant proportion of admissions could be avoided. An analysis by the King’s Fund suggests that while only 10 per cent of patients admitted as emergencies stay for more than two weeks, these patients account for 55 per cent of bed days. 80 per cent of these patients are over the age of 65.⁵² In the case of A&E attendances, BBC analysis of Freedom of Information data from 183 A&E departments revealed that 12,000 patients attended the same site more than 10 times in 2012-13.⁵³

“Recent research has demonstrated that pressure on hospital services is driven by a small number of patients, and that a significant proportion of admissions could be avoided.”

One of the principal drivers of cost in acute spending in recent years has been the rise in emergency admissions. A report by the National Audit Office calculated that the total number of emergency admissions had increased by 47 per cent in 15 years and the total cost had reached £12.5 billion in 2012-13.⁵⁴ 70 per cent of hospital beds are occupied by emergency admissions.⁵⁵ However a significant proportion of these admissions are preventable. Recent analysis by the Nuffield Trust found that one in five emergency admissions are for ambulatory care sensitive conditions (ACSCs) that could be treated in community settings.⁵⁶ Hospital admissions as a result of these conditions increased by 48 per cent over the 12 years from 2001 to 2013, more than the increase in other emergency admissions.⁵⁷ Similarly, NHS England estimated that 40 per cent of patients attending A&E are discharged requiring no treatment and over 1 million emergency hospital admissions in 2013 that were thought to be avoidable.⁵⁸

The failure to prevent these admissions is often attributed to poor coordination of care.⁵⁹ Poor coordination also has many further costs such as delayed discharges, readmissions, adverse incidents and medication errors. The total of these costs of “poor quality” is substantial yet largely unqualified.

51 Donnelly, L. et al. (2007), “Adherence to insulin and its association with glycaemic control in patients with type 2 diabetes”, *QJM*.

52 Poteliakhoff, E. and J. Thompson (2011), “Data briefing – Emergency bed use: what the numbers tell us”, King’s Fund.

53 Triggles, N. (2014), “A&E: Some patients visit units 50 times a year”, BBC Online, 7 January.

54 National Audit Office (2013), *Emergency admissions to hospital: managing the demand*.

55 Poteliakhoff, E. and Thompson, J. (2011), *Data briefing – Emergency bed use: what the numbers tell us*, King’s Fund.

56 Tian, Y. et al. (2012), *Data briefing – Emergency hospital admissions for ambulatory care-sensitive conditions: identifying the potential for reductions*, King’s Fund.

57 Blunt, I. (2013), *Trends in emergency admissions for ambulatory care sensitive conditions, 2001 to 2013*, Nuffield Trust and Health Foundation.

58 NHS England (2013), *Transforming urgent and emergency care services in England*.

59 Øvretveit, J. (2011), *Does clinical coordination improve quality and save money? Volume 2*, Health Foundation

2

The failure to fully engage

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“...in 2010 the then Health Secretary, Andrew Lansley, commented that in terms of patient engagement, ‘when you look at the Wanless report from 2002 and where we are today, we are on pretty much the poorest of those three scenarios. We are not in a fully engaged scenario.’”

“While the vast majority of patients are now aware of how personal behaviours affect their health and wellbeing, a large proportion admit to not consistently maintaining a healthy lifestyle.”

“The *Five Year Forward View* argued that this failure to take prevention seriously has put the NHS balance sheet at risk.”

On some measures the NHS has become more patient-centred in recent years. The National Inpatient Survey does show a gradual improvement in patient involvement in care. In the last decade patient choice, the NHS Constitution and various methods of capturing patient feedback have all been introduced. However the evidence suggests these policies have had limited impact so far. As the *Five Year Forward View* noted, “Twelve years ago, Derek Wanless’ health review warned that unless the country took prevention seriously we would be faced with a sharply rising burden of avoidable illness. That warning has not been heeded – and the NHS is on the hook for the consequences.”

To date the most authoritative assessment of progress towards the “fully engaged scenario” was produced by the King’s Fund in 2007.⁶⁰ While that report focused mainly on the impact of NHS funding on service improvement, the review nonetheless found only marginal improvements in population health measures and health determinants. The study concluded that the NHS was progressing broadly in line with the solid progress scenario, however identified that a more significant funding shortfall would emerge in the period up to 2013-14.⁶¹ Similarly, in evidence given to the Health Select Committee in 2010 the then Health Secretary, Andrew Lansley, commented that in terms of patient engagement, “when you look at the Wanless report from 2002 and where we are today, we are on pretty much the poorest of those three scenarios. We are not in a fully engaged scenario.”⁶²

Wanless did stipulate that patient engagement would require additional resource for the health service. It is therefore relevant to note that resource has not matched his projections, currently falling well short of the slow uptake scenario. However this does not excuse the failure to fully engage. Between 2002 and 2007 when the second review was undertaken public expenditure on healthcare rose rapidly and yet engagement remained somewhere between slow uptake and solid progress. Additional resource by itself cannot secure full engagement. Reform will be required to ensure the NHS is able to embrace the “expert patient”.

Healthy patients

While the majority of patients are now aware of how personal behaviours affect their health and wellbeing, a large proportion admit to not consistently maintaining a healthy lifestyle. The King’s Fund Review in 2007 found limited evidence of progress towards the Wanless ambitions. Levels of smoking in the population were found to match the solid progress scenario as were levels of physical activity. However, most concerning was that levels of obesity remained well below the slow uptake scenario and the quality of patient diets had not yet reached the solid progress scenario.⁶³

Progress in the years since has been equally disappointing. According to the latest *Health Survey for England* in 2012, a third of men and nearly half of women aged over 16 did not undertake the recommended level of exercise and nearly a third of men and a quarter of women aged over 16 had consumed more than twice the recommended alcohol intake.⁶⁴ While levels of smoking have declined, one in five adults continue to smoke. Most worryingly, levels of obesity are rising with almost two thirds of adults overweight or obese.⁶⁵

The *Five Year Forward View* argued that this failure to take prevention seriously has put the NHS balance sheet at risk. The cost of smoking related illness for example has been estimated at £5.2 billion each year while obesity costs the NHS £5 billion and the UK economy £15.8 billion annually.⁶⁶ “As the ‘stock’ of population health risk gets worse,

60 Wanless, D. (2007), *Our future health secured?*, King’s Fund.

61 Health Select Committee (2010), *Public expenditure*.

62 Health Select Committee (2010), *Responsibilities of the Secretary of State for Health: Minutes of evidence*.

63 Wanless, D. (2007), *Our future health secured?*, King’s Fund.

64 HSCIC (2012), *Health survey for England 2012*.

65 NHS England (2014), *Five Year Forward View*.

66 Allender et al. (2009), “The burden of smoking-related ill health in the UK”, *British Medical Journal*, Vol 18; Department of Health (2013), *News release: Reducing obesity and improving diet*, 25 March 2013; Public Health England (2014), *News release: Obesity and Health*.

“The National Inpatient Survey in 2013 found a number of patients are not as involved in their care as they could be.”

the ‘flow’ of costly NHS treatments increases as a consequence...Put bluntly, as the nation’s waistline keeps piling on the pounds, we’re piling on billions of pounds in future taxes just to pay for preventable illnesses.”

A patient-centred NHS?

Despite recent efforts to improve patient engagement the NHS has yet to achieve a truly patient-centred model of care. The National Inpatient Survey in 2013 found a number of patients are not as involved in their care as they could be. While 56 per cent of patients were “definitely” involved as much as they wanted to be in decisions about their care, 10 per cent were not involved as much as they wanted to be. Only 69 per cent of patients said that doctors and nurses “always” answered questions in a way that they could understand, and 20 per cent of patients were not given information about their condition and treatment. Moreover, less than half of respondents were given a “complete” explanation on any danger signals they should watch for once discharged.⁶⁷ Similarly, over 20 per cent of patients with chronic illness were not aware of different treatments that were available, suggesting they were not necessarily involved in decisions about their care.⁶⁸ The King’s Fund’s inquiry into the quality of general practice found that almost 30 per cent of patients, on average, felt poorly engaged in making decisions about their own health in 2009-10.

“Patient engagement continues to vary significantly between patients, often with those in the worst health the least engaged in their care.”

Patient engagement continues to vary significantly between patients, often with those in the worst health the least engaged in their care. A survey by the Health Foundation in 2005 found 33 per cent of patients who were in “poor health” did not know about different treatment options and 26 per cent were unaware of the options for self-treatment. This compares to 11 per cent and 9 per cent respectively for patients who rated their health as “excellent”. While 2 per cent of patients with “excellent” health lacked confidence to take remedial or preventative action, the number for patients in “poor” health was 29 per cent. Patients with chronic illnesses also appeared the least engaged, with 14 per cent believing they were unable to manage problems and symptoms. While some patients, such as those with diabetes, were confident with self monitoring their condition those with depression, lung disease or hypertension felt less able.⁶⁹

In this aspect of patient involvement, the relationship between patients and clinical professionals is significant. A review of NHS patient surveys by the Picker Institute concluded that “the most significant challenge for the NHS is to tackle the failure of clinical staff to provide active support for patient engagement.”⁷⁰ It identified little progress in moving away from “paternalistic approaches to care” in the NHS, stating that “opportunities to engage patients in their own care and treatment are frequently missed.”⁷¹ A recent King’s Fund report also identified that doctors often fail to consider patient preferences in clinical decisions because “they are rarely made aware that they have made a preference misdiagnosis” based on their preconceptions of what patients want.⁷² A survey of US and UK doctors found the views of clinicians were “out of step” with the growing consensus on the need to engage patients. While professionals strongly believe that patients should follow medical advice, they are less likely to agree that patients should be able to make independent judgements or actions.⁷³ Wanless’ vision of “tomorrow’s patient” was dependent on such a shift from a deferential patient to an active partnership between patient and clinician.

“A survey of US and UK doctors found the views of clinicians were “out of step” with the growing consensus on the need to engage patients.”

67 Care Quality Commission (2013), *National findings from the 2013 Inpatients Survey*.

68 Ellins, J. (2005), *How engaged are people in their health care? Findings of a national telephone survey*, Health Foundation.

69 Ibid.

70 Ibid.

71 Richards, N. and Coulter, A. (2007), *Is the NHS becoming more patient-centred? Trends from the national surveys of NHS patients in England 2002-2007*.

72 Mulley, A. et al. (2012), *Patients’ preferences matter: Stop the silent misdiagnosis*, King’s Fund.

73 Hibbard, J. et al. (2009), “The Development and Testing of a Measure Assessing Clinician Beliefs About Patient Self-Management”, *Health Expectations*, Vol.13.

“The NHS Constitution was established to drive greater patient engagement yet surveys have shown that few patients are aware of the NHS Constitution, and even fewer use it as a means to exercise their rights.”

“Only 51 per cent of patients are aware of the right to choice...”

“...the NHS has often struggled to engage with patients in a way which encourages their participation and engagement, rather than deters it.”

A consumer friendly NHS?

In recent years initiatives such as patient choice, the NHS Constitution and encouraging patient feedback have endeavoured to make the NHS more consumer focused, however these policies have had limited impact so far. The NHS Constitution was established to drive greater patient engagement yet surveys have shown that few patients are aware of the NHS Constitution, and even fewer use it as a means to exercise their rights. A survey commissioned by the Patients Association found that 76 per cent of patients had not heard of the Constitution before receiving treatment.⁷⁴ Only 2 per cent had an “excellent” understanding of it and over half felt it was “pretty meaningless”. A review by the Department of Health similarly found that the “the NHS Constitution is not yet having the effect originally intended.” Just 1 per cent of patients were found to have “cited the NHS Constitution as a source for finding out information about what they could expect from the NHS, their rights as patients, or what to do if they did not get what they expected”.⁷⁵ Crucially, over 98 per cent of patients reported being treated without being informed about the Constitution, either by staff or through leaflets.

Choice has also had a limited impact on patient engagement thus far. Only 51 per cent of patients are aware of the right to choice and 60 per cent said they were not offered a choice by their GP for an outpatient appointment.⁷⁶ 36 per cent of patients experience some sort of problem or difficulty when considering their choices, or expressed concern with the range of choice. Additionally, 63 per cent of hospital users and 65 per cent of social care users do not feel they had a choice of provider.⁷⁷ Patients continue to turn to GPs or friends and families, rather than NHS Choices, as a source of information. Giving patients access to personal health budgets and care plans was one of the key commitments of the Coalition Government. However progress has been slow and, as of last year, the number of personal health budgets implemented in each local area has barely exceeded 100 people.

Moreover the NHS has often struggled to engage with patients in a way which encourages their participation and engagement, rather than deters it. While patients often report their willingness to challenge and express preferences to their doctors, evidence suggests that few have the self-confidence to proactively engage. A survey by the Health Foundation suggests only 9 per cent of patients would ask for further clarification when they did not understand something their doctor had said.⁷⁸ The public is also less likely to complain about NHS services than other public or private services they use. A survey by Which? found that while 90 per cent of people who had cause to complain about a high street retailer did so, only 65 per cent of people who had cause to complain about an NHS service did so.⁷⁹ The Health Service Ombudsman similarly reported that, of the 18 per cent of people who wanted to complain, more than half did not and the CQC found that one in nine of patients are reluctant to speak out about poor quality care.⁸⁰

In most cases it is the unwillingness of the NHS to engage with consumers that deters patients from voicing concerns. Following the Francis Inquiry, the Department of Health commissioned an independent review of complaints procedures in the NHS. The review highlighted that patients often find the complaint process confusing, insensitive and uncoordinated. Patients also report being “frightened” about complaining and being “out gunned” by the provider.⁸¹ Ultimately, many patients found complaining ineffective. Survey

⁷⁴ Patients Association (2012), *The NHS Constitution: Fact or Fiction?*

⁷⁵ Department of Health (2012), *Report on the effect of the NHS Constitution*.

⁷⁶ NHS England and Monitor (2013), *Populus summary: outpatient appointment referrals*.

⁷⁷ Boyle, D. (2013), *The barriers to choice review*.

⁷⁸ Ellins, J. (2005), *How engaged are people in their health care? Findings of a national telephone survey*, Health Foundation.

⁷⁹ Public Administration Select Committee (2014), *More complaints please!*

⁸⁰ ICM Research (2013), *Fear of raising concerns about care: A research report for the Care Quality Commission*; Parliamentary and Health Service Ombudsman (2013), *Submission by the Health Service Ombudsman for England to the Review of the NHS Complaints System*.

⁸¹ Clwyd, A. and T. Hart (2013), *A Review of the NHS Hospitals Complaints System: Putting Patients Back in the Picture*, Department of Health.

“In many health systems, patient-centred care has been supported through innovations in IT and online access.”

“While some leading providers have developed sophisticated patient portals, the vast majority of patients are still unable to make appointments with GPs online or email their doctors.”

“There is also evidence of considerable confusion amongst the public when interacting with NHS services.”

data from the Health Service Ombudsman suggests that 64 per cent of patients who do complain think it will not make a difference.⁸² Another survey commissioned by the CQC also reported that more than half of patients who complained did not feel their feedback was welcomed. A similar number felt they did not receive a satisfactory response.⁸³

A digital NHS?

In many health systems, patient-centred care has been supported through innovations in IT and online access. However, the NHS's experience in putting patient records online and giving patients better remote access has been difficult. Successive reports have identified the NHS as a late, slow and disparate adopter of technology.⁸⁴ The National Programme for IT, subsequently Connecting for Health, has been the subject of numerous National Audit Office reports and Public Accounts Committee investigations. Before being scrapped in 2013, the programme was widely criticised for poor value for money and delays in introducing a single, interoperable care record to connect patients, GPs and hospitals. The rollout of online patient records has been repeatedly delayed and the current target is to achieve access for 95 per cent of patients by April 2015. However, GPs will only be required to provide access to the brief information held in the Summary Care Record.⁸⁵

NHS Direct and subsequently the 111 service have also been beset by problems and setbacks. While the telephone triage service has reduced some pressure on A&E and GPs, neither NHS Direct nor 111 have had the “disruptive” effect on the NHS that was hoped for. While uptake has increased over the last decade, relatively few patients use the service and high numbers are consequently referred to either a GP or A&E. NHS 111 experienced significant difficulties on launch with technical failures and inadequate staffing in some parts of the country. While some leading providers have developed sophisticated patient portals, the vast majority of patients are still unable to make appointments with GPs online or email their doctors.⁸⁶

Activated patients?

Patient “activation” has a significant impact on the effectiveness of healthcare interventions however large sections of the adult population have low levels of health literacy. A recent survey of over 7,000 middle aged patients found that a third have difficulties reading and understanding basic health related written information.⁸⁷ Approximately one-fifth of the UK population cannot read or follow basic instructions on medicine labels and it has been estimated that more than half are unlikely to be able to understand the cancer information brochures routinely available in hospitals.⁸⁸

There is also evidence of considerable confusion amongst the public when interacting with NHS services. A survey commissioned by HealthWatch England found that nearly a fifth of people admitted to using A&E for a non-emergency issue.⁸⁹ Many leading general practitioners have also highlighted the costs of treating the “worried well” which have been estimated to represent a fifth of all GP appointments.⁹⁰ Poor patient engagement is manifest in the limited awareness and use of alternatives. For example, according to the HealthWatch survey while 4 out of 5 people said they were aware of NHS 111, just 1 in 5 report having used it or its predecessor NHS Direct when in need of non-urgent care. Only 57 per cent of patients know how to contact an out-of-hours GP service.⁹¹

82 Parliamentary and Health Service Ombudsman (2013), *Submission by the Health Service Ombudsman for England to the Review of the NHS Complaints System*.

83 ICM Research (2013), *Fear of raising concerns about care: A research report for the Care Quality Commission*.

84 Liddell, A. et al. (2008), *Technology in the NHS: Transforming the patient's experience of care*, King's Fund.

85 Todd, R. (2013), “2015 records access promise scaled back”, *eHealth Insider*, 29 October.

86 Corrie, C. (ed.) (2014), *Disruptive innovation in public service reform, Reform*.

87 Bostock, S. and Steptoe, A. (2012), “Association between low functional health literacy and mortality in older adults: longitudinal cohort study”, *British Medical Journal*.

88 Richmond Group (2010), *How to deliver high quality, patient-centred, cost-effective care*.

89 HealthWatch (2014), “Nearly a fifth confess to knowingly using A&E for non-emergencies”, 4 March.

90 Iacobucci, G. (2010), “Fifth of appointments wasted on ‘worried well’, leading GPs warn”, *Pulse*, 16 March

91 Ipsos MORI (2013), *The GP Patient Survey: Summary Report*.

3

The emerging expert patient

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“It is quite possible the technology enabled “expert patient” will emerge more quickly outside the NHS than from within.”

The 2002 Wanless Review outlined a vision of “tomorrow’s patient.” As the world around the NHS was transformed by digital services and customer insight, expectations of the health service would grow. “Tomorrow’s patient” would be better informed, less deferential to clinical professionals and expect greater control over the service they use.⁹² In many ways “tomorrow’s patient” has arrived. Surveys show patients consistently want to be involved in their care. Patients are independently using technology to support their health and wellbeing but want to do more. Moreover individuals and their families already contribute a growing amount to their health and care, whether through informal care or rising gym membership.

Healthcare innovators have responded. A range of healthcare organisations around the world have been giving patients greater control over their health and the healthcare services they use. These have arisen both from within health systems but also often from the outside. Insurers and employers are also seeking to provide greater access to online and remote healthcare that is not typically offered by the NHS. For example, in 2014 a new application called Bablyon offered consumers access to a “virtual health service”.⁹³ Social networking sites such as IWantGreatCare and PatientsLikeMe have developed outside the traditional health system. It is quite possible the technology enabled “expert patient” will emerge more quickly outside the NHS than from within.

The emerging expert patient

“While patients have traditionally been regarded as passive users of the NHS, patients are engaging with their health in different ways outside of NHS services.”

While patients have traditionally been regarded as passive users of the NHS, patients are engaging with their health in different ways outside of NHS services. 80 per cent of all care in the UK is now self care and households are spending more time and resource on looking after their health than ever before.⁹⁴ Surveys consistently show that patients want more information about their health conditions and treatment options and the skills to self manage their condition. The expectation is now that they should be involved in decision about their care.

Patient surveys have consistently found that public appetite to be involved in the decisions which affect their care. More than 90 per cent of patients value their right to make choices about their healthcare according to the British Social Attitudes Survey and the National Patient Choice Survey. When asked what matters to individuals in their healthcare, over three quarters of the patients rank being involved in decisions as one of the most important factors.⁹⁵ Moreover many patients want to be more self reliant and better able to manage their condition with greater independence. An official survey by the Department of Health in 2005 found that 71 per cent of patients seek greater responsibility for their own health. 87 per cent of patients often treat a minor ailment themselves and 82 per cent of patients with long term conditions already play an active role in managing their own condition.⁹⁶

“Many patients are already using technology to monitor and manage their health.”

Recent trends have shown growing public interest in engaging with health not through traditional services, but through online and digital routes such as accessing health records, having a virtual GP consultation or ordering repeat prescriptions.⁹⁷ According to a 2013 survey, 97 per cent of consumers would like access to their electronic health records yet 67 per cent remain unable to do so.⁹⁸ Many patients are already using technology to monitor and manage their health. A study of 13 developed and developing countries found that nearly nine out of ten people have used the internet to find health information and advice.⁹⁹ A third of consumers aged 18-24 years report using online

92 Wanless, D. (2002), *Securing our future health*.

93 *Health Service Journal* (2014), “Parsa launches new ‘virtual health service’ app”, 28 April.

94 The Self Care Forum, “What do we mean by self care and why is it good for people”, accessed June 2014, www.selfcareforum.org/about-us/what-do-we-mean-by-self-care-and-why-is-good-for-people.

95 Department of Health (2004), *Choice, responsiveness and equity national consultation public survey*.

96 Department of Health (2005), *Public Attitudes to Self Care Baseline Survey*.

97 Bupa (2012), *Patient Power*.

98 Accenture (2013), *Consumer Survey of Patient Engagement Recap*.

99 Bupa (2012), *Patient Power*.

“The value of informal care is increasing faster than the cost of publicly funded health and care services...”

“For many households, investing in good health and healthy lifestyles represents a growing area of expenditure.”

“...few systems have introduced positive incentives to encourage healthy behaviours.”

resources to track their health while 60 per cent of patients would monitor their chronic condition using a mobile app.¹⁰⁰

Moreover individuals already make a significant investment in their health and wellbeing and that of their friends and family. Informal care has always been a key resource for the health service. There are an estimated 6.4 million unpaid carers in the UK. That equates to 12 per cent of the population and twice the number of paid staff in the NHS and care sectors.¹⁰¹ The contribution of unpaid carers in the NHS has been valued at £119 billion in 2011, more than public expenditure on NHS services. The value of informal care is increasing faster than the cost of publicly funded health and care services, having risen by 37 per cent between 2007 and 2011.¹⁰² In the case of dementia over a third of the costs (estimated at £23 billion a year) are met by informal care.¹⁰³ For cancer patients, friends and families contribute an estimated £2 billion on top of the £4.5 billion expenditure on care.¹⁰⁴ In social care, the NAO has estimated that the value of informal care is up to around £100 billion per year. That compares to the nearly £20 billion that local authorities spend on care.¹⁰⁵

For many households, investing in good health and healthy lifestyles represents a growing area of expenditure. According to the ONS, out of pocket annual household expenditure on healthcare rose by around 25 per cent between 1997 and 2013, from an average of £733 per year to £920 per year.¹⁰⁶ The total market for over-the-counter medicines has been estimated to be £2.4 billion and in 2012 households bought nearly a billion packets of over the counter medicines to self-medicate.¹⁰⁷ Consumer surveys have also demonstrated that gym membership and enrolment in wellbeing programmes, such as those for weight loss, nutrition advice and smoking cessation, have grown significantly.¹⁰⁸

Expert enablers

Leading healthcare providers, commissioners and entrepreneurs around the world are harnessing the emerging expert patient to improve outcomes and increase value. Below are four case studies of such innovations:

- Incentivising healthier lives through the **Vitality** insurance programme
- Patient led commissioning through **Personal Health Budgets**
- Online and remote healthcare support through **HealthConnect** at Kaiser Permanente
- Peer to peer support through **PatientsLikeMe** online community

Vitality

Changing individual behaviours is key to addressing the growing prevalence of chronic illness. Many countries and health systems have sought to curb excessive consumption of alcohol, fatty foods and smoking through introducing financial disincentives and tighter regulations. However few systems have introduced positive incentives to encourage healthy behaviours.¹⁰⁹ One exception is the Vitality insurance programme developed by Discovery Health in South Africa in 1993. It is has since been introduced in both the United States and the United Kingdom.

100 Accenture (2013), *Consumer Survey of Patient Engagement Recap.*; Patients.co.uk, August 2012

101 House of Lords Select Committee on Public Service and Demographic Change (2013), *Ready for ageing?*

102 Carers UK, Circle and University of Leeds (2011), *Valuing carers 2011.*

103 Alzheimer's Society (2014), *Dementia UK: Update.*

104 Sullivan, R. et al (2009), *Economic burden of cancer across the European Union: a population-based cost analysis.*

105 NAO (2014), *Adult social care in England: overview.*

106 ONS (2014), *Household Expenditure Estimates, 2013: Q4.*

107 Propriety Association of Great Britain, "Fast facts", accessed June 2014, <http://www.pagb.co.uk/media/facts.html>.

108 European Health and Fitness Association (2013), *The 2013 State of the UK Fitness Industry Report.*

109 Dixon-Fyle, S. and Kowallik, T. (2010), *Engaging consumers to manage health care demand*, McKinsey & Company; *The Economist*, (2011), "Getting on the treadmill", 8 October.

“Vitality applies the “air miles” model of consumer rewards to healthcare.”

“Hospital costs were 16 per cent lower for active members compared to inactive members over a five year period.”

“...the budgets allow patients to help define their health and wellbeing goals, select which services they receive and decide who delivers them.”

Method

Vitality applies the “air miles” model of consumer rewards to healthcare. Members are first risk profiled for levels of exercise, nutrition, mental wellbeing through online assessments, as well as further tests in an annual Health Check, to develop personal health goals. It then helps members meet these goals through a wide range of incentives and support designed to change behaviours. Members are incentivised to change their behaviours through earning “points” for exercising, buying healthy foods, hitting certain targets or participating in wellness programmes and further health assessments. For example, members can get between 10 and 25 per cent cash back on over 11,000 selected healthy foods at partner supermarkets and up to 25 per cent cash back on health products from a partner pharmacy chain. Similarly members can gain points for taking part in gym sessions, charity runs, using approved fitness apps or enrolling in weight loss and smoking cessation programmes. These points can then be used to purchase cinema tickets, frequent flier miles, reduced premiums and other discounts. Each member earns a Vitality status (blue, bronze, silver, gold and diamond) through engaging with the programme. The higher the status earned, the larger the discount.¹¹⁰

Outcomes

Today Vitality has nearly 1.7 million members and is the market leader in South Africa and has a global membership base of 5.5 million. A number of studies have demonstrated that Vitality’s members are healthier and more engaged in their health than non-Vitality members.¹¹¹ Analysis of the HealthyFood initiative, where members are incentivised to purchase healthy foods, found that the incentives increased the ratio of healthy to total food expenditure by 9.3 per cent and decreased the ratio of less desirable food items by 7.2 per cent. Vitality research also shows that gym membership and usage increases the longer a member remains on Vitality. Similarly, an analysis of 300,000 people over a five year period found that the percentage of members using the gym at least once a week increased by 23 per cent. During this period the proportion of members classified “highly engaged” increased from 12 to 20 per cent and those classified as “not engaged” fell from 49 to 30 per cent. Research has also demonstrated that these healthy behaviours have an impact on the cost of healthcare. Hospital costs were 16 per cent lower for active members compared to inactive members over a five year period. Active members were also less likely to be admitted to hospital and more likely to have a shorter length of stay.

Personal Health Budgets

Personal health budgets (PHBs) are designed to give people greater control and choice by allocating individuals the NHS money to purchase the services they seek to use. In this way the budgets allow patients to help define their health and wellbeing goals, select which services they receive and decide who delivers them. The evidence indicates that this choice and control has meant patients felt their physical and mental health was improved and it proved more cost-effective for NHS services. This co-production of the patient’s health and wellbeing goals is designed to allow individuals access to the latest science and evidence and to medical advice while empowering individuals to directly decide how they want to go about their care. In this way the money will follow the patient, not the other way around. The challenge now remains to translate these pilots to a national scale.

Co-designing a personal health budget

The core of the personal health budget is an individual care plan to harness the expertise of clinicians, the individual and their family. The care plan is based on an

¹¹⁰ Nossel, C. (2011), *The Vitality Wellness Programme: Experience from South Africa*, Discovery.

¹¹¹ Volpp, K. (2014), *The Case for Incentivising Health: Using behavioural economics to improve health and wellness*, AIA Australia; Discovery Vitality, (2014), *Do Well*.

assessment of the health needs of the individual and the cash value of NHS money they are entitled to. Beyond this, the goals and how they are met are set by the individual with the advice of their clinician. There is no set menu of services; if the patient decides their health needs are best met by buying gym membership or a computer then they are able to do so. By allowing for greater patient control, it is hoped that individuals will be encouraged to better adhere to the care plan agreed upon. The plan is approved on the basis of being financially and clinically appropriate given their goals. Once signed off by a clinician and their commissioner, individuals are then given the choice over how and when they receive and spend their allocated budget. Individuals can receive the budget as a direct payment that they manage themselves, it can be managed by a third party, or it can be held by a provider or commissioner.

“...personal health budget holders perceived their health and wellbeing to have improved and used on average £1,400 a year less inpatient, A&E, and GP care than those receiving traditional services.”

The plan is intended to cover discrete aspects of ongoing care, such as psychological therapy, rather than an individual's entire health needs. GP services, pharmaceuticals and emergency services are explicitly not included. The scope of the budget therefore varies greatly, with some PHBs covering the value of an individual's entire continuing health care package, worth as much as £150,000, while others were for simply additional supports, costing less than £500. The average budget size was therefore £10,000 a year, however over half of all the PHBs in the pilot programme were worth less than that. The pilot suggests that it is these larger-value budgets where patients are given the most choice and flexibility and where they can pursue the best value for money.

Outcomes

The Department of Health launched a pilot in 2009 over 70 PCTs and a range of long term conditions, NHS continuing health care, maternity care and end of life care. The evaluation of the pilot concluded that personal health budgets are, on the whole, cost-effective and therefore recommended their full roll out nation-wide. The pilot found that personal health budget holders perceived their health and wellbeing to have improved and used on average £1,400 a year less inpatient, A&E, and GP care than those receiving traditional services. The approach was more cost effective for those with larger budgets, suggesting that there are more savings to be made from those with higher levels of need.

The main findings of the evaluation are summarised below:¹¹²

- > **Quality:** Personal health budgets showed significant improvement on care-related quality of life and psychological wellbeing but did not significantly impact on clinical outcomes or health-related quality of life.
- > **Cost:** Inpatient, A&E and GP costs were reduced compared to the control group. While total costs were not significantly different, this was in large part due to the direct costs of PHBs that were offered in addition to conventional service delivery. This duplication thus cancelled out savings.
- > **Cost-effectiveness:** Using care-related quality of life measures, PHBs were more cost-effective than conventional service delivery.
- > **Variation:** High value PHBs (those over £1,000 per annum) were found to be more cost-effective than low value budgets. The net benefit of PHBs for continuing health care and mental health were greater than for other patient groups.
- > **Supporting carers:** Carers were more likely to report better quality of life and perceived health.
- > **Equity:** There was no evidence of inequity of outcomes by age, sex or socioeconomic status.

¹¹² Alakeson, V. and Rumbold, B. (2013), *Personal health budgets: Challenges for commissioners and policy-makers*, The Nuffield Trust; NHS England (2012), *Personal health budgets pilot – final evaluation report*.

The results of the pilot concurred with evidence from international health studies and from the experience of individual budgets in social care in England.¹¹³ Like in these schemes, the budget holders perceived their health and wellbeing to improve and pursued value for money from the resources they were given, for example by negotiating prices with providers.¹¹⁴ While concerns have been raised that personal health budgets involve a greater degree of risk for the patient, this risk is managed by ensuring that all care plans are signed off by a clinician before being approved by commissioners. Moreover, where individuals choose to hire their own staff this encourages a higher level of trust between the individual and their care team, which in turn reduces risk.¹¹⁵

An opportunity for patient-led integration

Bringing personal health budgets together with personal budgets in social care to create integrated individual budgets potentially offer a new route to service integration at the level of the user and carer. With over 300,000 personal budget holders in social care, there is a significant opportunity for NHS providers to work together with local health partners to deliver more joined up personalised services and budgets. In the PHB pilots a number of areas developed a “dual carriageway” to create a coordinated process of referral, assessment, budget setting, planning and monitoring of different budgets without the more complex structural integration of organisations. This offers an opportunity to join up services for patients with minimal disruptive change.¹¹⁶

Achieving scale

NHS England has set out the ambition to ensure all patients with a long term condition, frail elderly people, disabled children and people with a serious mental illness or learning disability have the right to a digitally accessible care plan and a PHB by April 2015.¹¹⁷ This represents a considerable extension of the programme. Achieving this scale will present new challenges for commissioners to ensure PHBs deliver the same benefits. As Vidhya Alakeson, former Mental Health Lead for NHS England Personal Health Budgets Delivery Programme, has explained, “the biggest challenge for commissioners is to unlock money from existing contracts. NHS providers will have to change the way they do things or lose out to new entrants. Budget holders will demand greater flexibility and a broader, more preventive range of care services than the NHS currently buys. For clinicians, it will mean a willingness to explore new approaches to meeting long-term health needs.”¹¹⁸

For commissioners this means supporting the creation of a market diverse enough to cater for the range of needs of individual budget holders. This could be achieved by encouraging new market entrants, though it will be important for commissioners to work with budget holders and their families to understand what they expect and currently lack from the market. However CCGs will also need to decommission those services not chosen by budget holders. At the minute the small scale of the scheme means there hasn't been a large degree of duplication, however as of April 2014 this will become a significant risk for commissioners to avoid. CCGs will also need to fund new infrastructure around budget setting, care planning and system monitoring. This funding will need to be found in existing budgets. There is some evidence to suggest that some efficiency can be achieved by “piggy-backing” on the systems that already exist to support personal budgets in social care or to existing finance infrastructure, as in Nene Clinical Commissioning Group in Northamptonshire which has been trialling mental health payment by results as the basis for allocating resources for personal health budgets.

113 Health Foundation (2010), *Personal health budgets: Research scan*.

114 Fox, A. (2012), *Personalisation: lessons from social care*, RSA.

115 Alakeson, V. and Rumbold, B. (2013), *Personal health budgets: Challenges for commissioners and policy-makers*, The Nuffield Trust;

116 NHS Confederation (2012), *Joint personal budgets: a new solution to the problem of integrated care?*

117 Department of Health (2013), “£1 billion to help A&Es and NHS staff access medical records in hi-tech hospital revolution”, press release, 4 September; NHS England (2013), *NHS Planning Guidance December 2013*; Campbell, D. (2014), “NHS chief announces plan to give patients cash to fund their own care”, *The Guardian*, Tuesday 8.

118 Alakeson, V. (2014), “Personal health budgets will transform care for people with long-term needs,” 7 January, *The Guardian*.

“...integrated individual budgets potentially offers a new route to service integration at the level of the user and carer.”

“...information technology has been an important driver of patient engagement.”

HealthConnect

The use of information technology has been an important driver of patient engagement. Surveys have demonstrated that many patients would like to access health information and manage their healthcare online, as can be done in many other industries.¹¹⁹ Other surveys have suggested that patients are more likely to be engaged in their health and make better choices about their care if they have easy access to information. Online access is also an important enabler of self-management for patients with chronic conditions. In recent years many leading providers have developed both electronic health records (EHRs) and online patient portals that can both give patients their health information online and improve communication between patients and providers. The use of patient portals has become particularly widespread in the United States with the Kaiser Permanente HealthConnect system being a leading example.

Kaiser Permanente's HealthConnect

Kaiser Permanente is the largest not-for-profit, integrated health care delivery system in the United States with 9.1 million members.¹²⁰ Kaiser has long been a celebrated exemplar of integrated care and effective use of information technology has been central to its approach to patient-centred coordinated care. While the use of electronic health records dates back to the 1990s, in 2003 Kaiser launched its current system of EHRs, HealthConnect. In 2007, Kaiser launched My Health Manager, the primary patient portal.¹²¹ The system has a number of functions: patients can view their personal health information, including lab results, health conditions and their past consultations; schedule and cancel appointments; refill prescriptions; email doctors and other staff; and take online health assessments and access health information. Patients can access My Health Manager anywhere in the world, 24/7 and now through mobile apps.

Uptake

Patient uptake of the online patient portal has been strong. Between 2005 and 2008 the number of registrations tripled as the more functions were added to the website and patient awareness grew.¹²² The number of visits to the website also tripled between 2004 and 2007. Today, all Kaiser's members have the benefit of a complete HealthConnect record and 4.4 million are registered to use My Health Manager. Each month, 2.9 million lab results are accessed online, patients send 1.2 emails to clinicians, 1.2 million prescriptions are refilled and 300,000 appointments are scheduled. Those registered are more likely to be female and between the age of 40 and 60.¹²³

Outcomes

The growing use of HealthConnect and My Health Manager have both improved patient behaviours and made Kaiser more efficient. A study of Kaiser members in Hawaii (the region that was to first implement HealthConnect for outpatient services) found that between 2004 and 2007 the number of office visits by patients fell by over a quarter. By contrast scheduled telephone consultations increased eightfold.¹²⁴ A similar study of patients in the Northwest region found that that visits to primary care physicians fell by over 10 per cent between 2005 and 2007.¹²⁵ Email communication has the benefit of improving continuity of care and giving patients greater confidence to self-manage. One study of patients with diabetes and hypertension found that regular emails between

119 Emont, S. (2011), *Measuring the impact of patient portals: what the literature tells us*, California Healthcare Foundation.

120 McCarthy, D. (2009), *Kaiser Permanente: Bridging the quality divide with integrated practice, group accountability and health information technology*, The Commonwealth Fund.

121 Institute for Health Policy (2012), *Kaiser Permanente Policy Story: Engaging patients online with My Health Manager*.

122 Allen, J. (2009), "If You Build It, Will They Come? The Kaiser Permanente Model Of Online Health Care", *Health Affairs*.

123 Kaiser Permanente, "About us: total health connectivity", accessed June 2014, <http://share.kaiserpermanente.org/total-health/connectivity>.

124 Chen, C. et al. (2009), "The Kaiser Permanente Electronic Health Record: transforming and streamlining modalities of care", *Health Affairs*, vol.28 no.2.

125 Baer, D. (2011), "Patient-physician e-mail communication: the Kaiser Permanente experience" in *Journal of Oncology Practice*, vol.7 no.4.

“The growing use of HealthConnect and My Health Manager have both improved patient behaviours and made Kaiser more efficient.”

patients and doctors led to better control of blood pressure and blood glucose levels.¹²⁶ While doctors were initially concerned that receiving emails would increase their workload, most soon felt that enabling email access improves their efficiency and quality of care they provide. Surveys have also demonstrated very high levels of patient satisfaction with the system.

PatientsLikeMe

There is growing interest in the potential of e-health to help manage the rising burden of chronic disease by reducing duplication and waste, improving the quality of care through improved communication and data, and empowering patients to manage their own health. Recent years have seen the emergence of a number of online peer-to-peer support networks to enable patients to share their experiences and learn from each others'. PatientsLikeMe (PLM) is one such online community. Established in 2004 by three MIT graduates, PLM aims to help patients to answer the question, "Given my status, what is the best outcome that I can hope to achieve and how do I get there?" By better informing patients about their conditions and what to expect and providing this through an easily accessible digital platform, PLM empowers patients to have a more informed discussion with their clinician.¹²⁷ Named one of the "15 companies that will change the world" by CNN Money, the PatientsLikeMe model of an online platform for patient learning has become increasingly influential.

Building patient communities

PatientsLikeMe consists of online patient communities to group users by relevant experiences. When a patient first signs up they are asked to join a particular community (based on disease), establish an anonymised username and enter information about their condition, from symptoms to reactions to treatments. PLM is unique to other social media health companies in the depth of data it collects and the degree to which it shared it with its members. Patients are encouraged to continue entering as their condition and treatment progresses. While the majority of patients choose to share their data only with other patients in the community, over 10 per cent choose to make their information publicly available to anyone on the PLM site.¹²⁸ Within its first five years PLM built a community of over 80,000 patients, with 15 patient communities covering 19 diseases and it continues to expand rapidly; in 2010 PLM decided to extend their online community through a "general platform" to allow anyone with any condition to join and participate.

Learning from experience

By sharing the experiences of a broad range of patients, users are able to learn about their condition through the experience of others. Similarly patients are able to use the information they find to improve their own outcomes and use the website to track their condition. The use of PLM by users of an epilepsy community found a number of benefits to this increased learning. 55 per cent agreed it helped them learn more about seizures, 27 per cent agreed it helped them be more adherent to their medication, 27 per cent said it helped them reduce the side effects of treatments, and 18 per cent suggested they needed fewer visits to the emergency room, all directly as a result of their interactions on the site.¹²⁹

Empowering patients

PLM is founded on the principle that transparency and open data can empower patients not simply through improved understanding but also enabling patients to be more

"There is growing interest in the potential of e-health to help manage the rising burden of chronic disease"

"...users are able to learn about their condition through the experience of others."

126 Zhou, YY. et al. (2010), "Improved quality at Kaiser Permanente through e-mail between physicians and patients" in *Health Affairs*, vol. 29 no. 7.

127 Ahmed, S. et. Al (2013), "Innovations in e-health", *Quality of Life Research*.

128 S. Gupta et al. (2011), "PatientsLikeMe: An online community of patients", *Harvard Business Review*.

129 Wicks, P. and Hixon, J. (2013), "The Patient Engagement Pill: Lessons from Epilepsy", *Health Affairs*, February 7.

“Patients who use social platforms such as PLM to connect with one another have been found to be more likely to engage in other behaviours that support engagement, such as antenatal classes, WeightWatchers or Alcoholics Anonymous.”

engaged in the decisions which affect their health. Firstly, the information entered gives PLM members ownership of an easily accessible two-page report summarising their medical history. The shared learning from the online community along with this medical record enables patients to engage in a more informed conversation with their clinician. Suggestions from their online community have been proven to prompt patients to ask their clinician to conduct new tests or prescribe different medications. For example, patients using PLM are able to get a summary report about a drug including side effects, typical dosage and why they stopped taking it. Almost 11 per cent of members switched their doctor based on their learning at PLM.¹³⁰

An alternative model of support

Evidence suggests that the number of social ties with other patients with the same condition influences the number of benefits they experience. In the case of epilepsy, despite a mean seizure duration of 23 years, prior to joining the site one in three epilepsy patients said they didn't know anyone else with epilepsy with whom they could discuss their condition. After joining the site, two-thirds of these previously isolated patients reported knowing at least one person they could connect with. Patients report that this informal shared learning with patients is often preferred to the more formal consultation with their clinician.¹³¹ Further, these benefits can be extended to other areas of their health. Patients who use social platforms such as PLM to connect with one another have been found to be more likely to engage in other behaviours that support engagement, such as antenatal classes, WeightWatchers or Alcoholics Anonymous.¹³²

¹³⁰ Ibid.

¹³¹ Ibid.

¹³² Ibid.

4

Progress on patient engagement

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“With long term conditions consuming an estimated 70 per cent of healthcare resource, supporting these individuals to better manage their own conditions has become a focus for the health service.”

Successive governments have sought to make healthcare more patient-centred and responsive. Since the NHS Plan in 2000, involving patients in the decisions which affect their health and supporting patients to manage their conditions have been at the heart of health reform.¹³³ Under the Coalition, the 2010 NHS White Paper set out an ambition of “no decision about me without me” and the NHS Mandate put forward the duty to “ensure the NHS becomes dramatically better at involving patients.”¹³⁴ Various initiatives such as the Friends and Family Test and electronic patient records have increasingly sought to engage patients as consumers.

A healthy society

Improving public health through prevention and engagement was identified by Derek Wanless as a key factor in ensuring the long term sustainability of health spending.¹³⁵ Back in 2004, the public health White Paper set out a number of ways to provide people with the information and advice they need to support healthy lifestyle choices from Health Direct to chronic disease management in pharmacies.¹³⁶ Under the Coalition much focus has been given to empowering local communities to improve public health with the creation of Public Health England and health and wellbeing boards, designed to coordinate efforts between the NHS and local government.¹³⁷

With long term conditions consuming an estimated 70 per cent of healthcare resource, supporting these individuals to better manage their own conditions has become a focus for the health service. The NHS has sought to develop a number of tools to support self care, including personalised action plans, structured education and information, access to advice and coaching from clinicians and peer-led support programmes, such as the Expert Patients and Patients in Control programmes.¹³⁸ There has also been growing investment in telehealth and telecare to allow more patients to take a greater role in their own treatment and monitoring of their health from the home, with 3 million patients set to benefit by 2017.¹³⁹

A patient-centred NHS

The NHS in recent years has endeavoured to support patients to take a greater role in the decisions which affect their care. Some efforts have focused on making shared decision making the default across the NHS. The Right Care Shared Decision Making programme has helped develop training and education resources to embed shared decision-making in the curricula for a range of healthcare staff, worked to raise awareness of shared decision-making amongst patients, their family and carers, and developed a range of patient decision aids.¹⁴⁰ In recent years personalised care plans and personal health budgets have been introduced to build the health and care plan of an individual through partnership between the patient and the clinician. This has been a particular focus of efforts to engage patients with long term conditions. By April 2015 all patients with a long term condition, frail elderly people, disabled children and people with a serious mental illness or learning disability will have the right to a digitally accessible care plan and a personal health budget.¹⁴¹

Efforts to reform and integrate health and care services have increasingly recognised the importance of harnessing patient involvement and achieving the outcomes that matter

“Efforts to reform and integrate health and care services have increasingly recognised the importance of harnessing patient involvement.”

133 Department of Health (2000), *The NHS Plan: a plan for investment, a plan for reform*.

134 Department of Health (2010), *Equity and excellence: Liberating the NHS*.

135 Wanless, D. (2002), *Securing our Future Health: Taking a Long-Term View*.

136 Department of Health (2004), *Choosing health: making healthy choices easier*.

137 HM Government (2010), *Healthy lives, healthy people*.

138 NHS England (2013), *Transforming participation in health and care*.

139 Healthcare UK (2014), *Digital health: working in partnership*.

140 Department of Health (2012), *Liberating the NHS: No decision about me, without me, Government response*.

141 Department of Health (2013), “£1 billion to help A&Es and NHS staff access medical records in hi-tech hospital revolution”, press release, 4 September; NHS England (2013), *NHS Planning Guidance December 2013*; Campbell, D. (2014), “NHS chief announces plan to give patients cash to fund their own care”, *The Guardian*, Tuesday 8.

“Over the last decade there have been efforts to move healthcare resources online to help patients to engage in shared decision-making, self care and informed choice.”

to patients. Back in 2006, the *Our health, our care, our say* White Paper highlighted the importance of coordinating services to give people greater independence and control over their lives as well as making the services in turn more flexible and responsive to patient needs. This Parliament has seen a number of initiatives to further integrate services, from the Better Care Fund to the 14 Integration Pioneers. The NHS Future Forum Report in 2012 concluded that “There has been too much focus on different parts of the system – GPs, hospitals, public health – and insufficient attention to how they all join up to provide the integrated care that patients need.”¹⁴² In 2012 NHS England commissioned National Voices to construct a narrative for person-centred, coordinated care. This consisted of a series of “I” statements to give efforts to integrate services a unifying vision around patient empowerment and engagement in their care, such as “I tell my story once”, “I have information, and support to use it” and “I am as involved as I want to be in decisions about my care.”¹⁴³ In October 2014, the *Five Year Forward View* set out a number of new models of care to better join up local health economies. Multispecialty community providers or primary and acute systems were envisaged as more sustainable new organisational models which could in turn better coordinate care for patients as they travel through different health and care services.¹⁴⁴

In recent years there has also been growing interest in outcomes based commissioning as a route to coordinating care around particular patient pathways and rewarding providers for the outcomes which matter to patients, not simply on volume of activity.¹⁴⁵ In Cambridgeshire and Peterborough, for example, the CCG has awarded a consortium of NHS hospitals the contract to manage care for frail and elderly citizens across different services.¹⁴⁶ A number of CCGs are exploring similar contracts for areas such as MSK and mental health.

A digital NHS

Over the last decade there have been efforts to move healthcare resources online to help patients to engage in shared decision-making, self care and informed choice. Preceded by NHS Direct Online, the NHS Choices website is now the largest healthcare online resource from information on over 750 conditions and treatments, to the Patient Insight Dashboard and most recently MyNHS to allow patients to compare GP surgeries, hospitals and clinical commissioning groups. Resources are also included to support shared decision-making, including the Department of Health’s prompt sheet for patients, *Questions to ask*, which suggests a series of questions that patients may want to ask their doctor about their condition and treatment options. To support the public and patients to use these online resources, “digital health hubs” are being developed in public places such as libraries and pubs to offer training and support for websites such as NHS Choices, providing feedback on NHS organisations or ordering repeat prescriptions online.¹⁴⁷

There are also efforts to improve patient access to information about their own health and care. For a number of years the NHS has worked to gather a Summary Care Record for NHS patients as part of the NHS Connecting for Health programme and the Coalition has pledged that by 2015 patients will be guaranteed access to their own GP health record.¹⁴⁸ In Autumn 2014 the *Five Year Forward View* and the National Information Board committed to expanding the number of NHS accredited health and care apps and other digital services for patients to use, including some able to be prescribed by local GPs.¹⁴⁹

142 Department of Health (2011), *NHS Future Forum*.

143 National Voices (2012), *A narrative for person-centred coordinated care*.

144 NHS England (2014), *Five Year Forward View*.

145 Corrigan, P. and Parish, M. (2014), *Going with change*.

146 Illman, J. (2013), “CCG tenders integrated older people’s service worth up to £1 billion”, *Health Service Journal*.

147 NHS England (2013), “Up to 100,000 people to use the internet to improve their health”, press release, 13 March.

148 Department of Health (2012), *The power of information*.

149 National Information Board (2014), *Personalised health and care 2020*.

Table 4: Key initiatives and publications since 2002

Year	Announcement	Detail
2002	Wanless Review	The Review emphasised the need for public engagement in their health as among those factors necessary to ensure the sustainability of health spending.
2002	Expert Patient Programme first piloted	Self-management training course for patients with long term conditions. Piloted from 2002-2004 and subsequently rolled out nationwide.
2003	Building on the best: Choice, Responsiveness and Equity in the NHS	Expansion of choice from elective surgery to the choice of 4-5 hospitals at the point of referral from late 2005, with the ability to book electronically from their GP surgery, as well as widening choice in maternity services and over end of life care. Increased access to alternative sources of clinical advice such as chronic disease monitoring at local pharmacies and patients given ability to annotate their personal health record with information and preferences in a "HealthSpace" linked to their electronic health record.
2004	<i>Choosing Health: Making healthy choices easier</i>	The Public Health White Paper set out a number of measures including the introduction of health trainers and Health Direct to provide people with information and advice to support healthy lifestyle choices.
2004	<i>Choose and Book introduced</i>	By December 2005 all patients were able to choose and book hospital appointments through their GP surgery.
2005	Choice introduced	Piloted from 2002-3, in late 2005 patients are given choice of four hospitals at GP referral. By 2008 this is extended to "free choice" of any eligible hospital at referral for their first outpatient appointment.
2006	<i>Our health, our care, our say: A new direction for community services</i>	The roll out of individual care plans for all patients with long term conditions by 2010. Investment in the Expert Patients Programme was trebled, increasing the course capacity from 12,000 to 100,000 by 2012.
2007	NHS Choices introduced	Established to give patients information to better make choices about their health, including between treatment options and healthcare providers. Replaced NHS Direct Online.
2009	NHS Constitution	The Constitution set out for the first time what patients have the right to expect from the NHS, including the right to choice and to be involved in decisions which affect their care, and a duty of patients to use NHS services responsibly.
2010	<i>Healthy lives, healthy people</i>	A public health strategy that "empowers individuals to make healthy choices and gives communities the tools to address their own, particular needs." New emphasis on communities and local government as the unit and leaders of public health.
2010	<i>Equity and Excellence: Liberating the NHS</i>	Extension of patient choice of any qualified provider, of named consultant-led team for elective care by April 2013, choice of diagnostic testing from 2011, choice in care for long term conditions and in end of life care, choice of GP practice and consultation on choice of treatment. Choice in maternity extended through new maternity networks. Supported through an "information revolution" for patients, including access to health records, and strengthening patient voice, through wider use of PROMS, patient experience data and real time feedback.

2012	<i>Liberating the NHS: No decision about me without me, Government response</i>	Announced a Choice Framework will be launched to set out what choices patients can expect to be offered. A new pledge also to be included in the NHS Constitution to involve patients in care planning discussions.
2012	<i>The power of information: Putting all of us in control of health and care information we need</i>	Outlines ambition for the NHS and social care is to be “digital first”. All GP surgeries will be expected to give patients access to an electronic record, offer electronic booking, ordering of repeat prescriptions and communication with the practice by 2015. This information will be published on NHS Choices from 2013.
2012	2013-14 Choice Framework	The Choice Framework sets out patient choice of GP practice, first outpatient appointment, consultant led team, hospital, maternity service and community service.
2013	Friends and Family Test	Piloted in 2012, the Friends and Family Test was rolled out in 2013 across all NHS trusts. The test will be extended to cover all NHS services by the end of 2014-15.
2013	NHS Mandate	The Mandate set out a duty to “ensure the NHS becomes dramatically better at involving patients...empowering them to manage and make decisions about their own care and treatment.” Committed that by 2015 everyone with a long term condition (including mental health problems) will be offered a personal care plan, option to hold their own health budget, all patients will have access to their GP health record, wider availability of e-consultations and more people with long term conditions able to benefit from telehealth and telecare by 2017.
2013	Francis Review	Following a failure to identify and address poor care at Mid Staffordshire NHS Foundation Trust, in February 2013 Robert Francis QC laid out 290 recommendations to create a common patient-centred culture across the NHS.
2013	Launch of Healthwatch England	Healthwatch England and local Healthwatch organisations established to act as the national consumer champion in health and care.
2013	Berwick Review	In August, Don Berwick’s review into patient safety in the NHS highlighted patient voice and participation as key tools to root out poor performing organisations.
2013	<i>Urgent and Emergency Care Review</i>	In November, the Review by NHS England identified better quality and more accessible information about self treatment options as a key part of managing demand on urgent and emergency care services.
2014	<i>Five Year Forward View</i>	Committed to a radical upgrade in prevention and public health and giving patients greater control over their own care through the better use of technology and improved partnership with community resources.
2014	<i>Personalised Health and Care 2020</i>	Strategy published by the National Information Board. Pledged to expand the number of NHS accredited health and care apps and other digital services to enable patients to make informed choices.

“NHS England has given a renewed focus to open data on outcomes as important metrics of quality”

A consumer friendly NHS

Providing patients with choice over their healthcare has been a priority for the NHS over the last decade. Following the first patient choice pilots back in 2002, the 2003 White Paper set out plans to extend patient choice to 4-5 hospitals at the point of referral and by 2008 patients were able to select any eligible hospital at GP referral through Choose and Book.¹⁵⁰ Under the Coalition, the Open Public Services agenda sought to promote choice across all public services. The 2010 NHS White Paper, *Equity and Excellence*, laid out their vision of patient-centred care where there is “no decision about me without me.” This saw patients given choice over GP practice, their first outpatient appointment, choice of consultant led team, and choice of hospital provider. Now over 80 per cent of all bookings using Choose and Book are made to a service listed against a named consultant and from April 2014 all patients are entitled to choice over their preferred mental healthcare provider as well.¹⁵¹ In primary care, following the GP choice pilots from October 2014, choice of GP practice will be rolled out across England.

This Parliament, NHS England has given a renewed focus to open data on outcomes as important metrics of quality and as a means of giving patients more meaningful choices between services and treatments. The introduction of a ratings system for hospitals and care homes in 2013 was designed to allow patients to better compare provider performance while patients now have access to surgeon-level clinical outcomes data across 10 specialities on the NHS Choices website. This data will be extended across more treatments and conditions as well as publishing more overarching clinical indicators to allow the public to tell how well services are performing across clinical areas, for example cancer. Data from all appropriate NHS funded national clinical audits is to be made publically available by 2020.

“Alongside clinical indicators, patient feedback is now collected as a key measure of quality of care.”

There have also been efforts to give patients clear rights and responsibilities, with the 2009 NHS Constitution setting out in writing for the first time what patients have the right to expect from the NHS and a duty for patients to use services responsibly in turn. These rights include both the right to choice and to be involved in decisions which affect their care. In recent years there have been efforts to strengthen the Constitution and to raise awareness amongst patients, clinicians and the public. The Future Forum in 2012 recommended that the content could be strengthened through a greater focus on staff engagement, the need to ask for and act upon feedback and greater emphasis on patient and carer involvement and shared decision making.¹⁵² In 2014 an Expert Advisory Group produced a series of recommendations to better embed the Constitution. These included improving access to the Constitution through online, developing concise versions tailored to patient groups, developing metrics of patient engagement for NHS organisations, and defining the rights in the Constitution less as abstract principles and more as specific behaviours.¹⁵³

Another route to engaging patients in their healthcare has been through use of patient feedback. Alongside clinical indicators, patient feedback is now collected as a key measure of quality of care. Online communities such as Dr Foster, iWantGreatCare and PatientsLikeMe are some such innovations. Similarly, the Friends and Family Test is the first time a single measure of patient satisfaction has been applied to every hospital and the results made public monthly through the NHS Choices website. From 2013-14 the Test will be extended to maternity services, GP practices, community care and mental health services, covering all NHS services by the end of March 2015. There has also been growing interest in patient defined outcomes, with 20 initiatives launched in

¹⁵⁰ Department of Health (2003), *Building on the Best: Choice, Responsiveness and Equity in the NHS*.

¹⁵¹ Department of Health (2012), “More choice in mental health”, press release, 13 December.

¹⁵² Future Forum Working Group (2012), *Letter to the Secretary of State for Health from the NHS Future Forum working group on the NHS Constitution*.

¹⁵³ Expert Advisory Group (2014), *Next steps for the NHS Constitution*.

“These new metrics of patient experience have been implemented against the backdrop of growing interest in how the NHS can better harness patient voice to drive up standards of quality and safety.

specialised services in 2012 for patients to measure their outcomes and share them with other patients if they choose to.¹⁵⁴

These new metrics of patient experience have been implemented against the backdrop of growing interest in how the NHS can better harness patient voice to drive up standards of quality and safety. A number of reviews this Parliament have sought to address instances of unsafe care and to recommend system wide solutions. The Francis Inquiry in 2013 laid out 290 recommendations to foster a common patient-centred culture across the NHS as a crucial part of preventing instances of unsafe care. This was highlighted further by the Berwick Review into patient safety which concluded that “Patient involvement is crucial to the delivery of appropriate, meaningful and safe healthcare...The goal is to achieve a pervasive culture that welcomes authentic patient partnership – in their own care.”¹⁵⁵ The report recommended firstly that patients and the public should have access to “all data on quality and safety” and that “all organisations should seek out the patient and carer voice as an essential asset in monitoring the safety and quality of care.”¹⁵⁶ There have also been parallel efforts to improve hospital complaints systems and give patients greater confidence in their ability to raise concerns, following a review by Ann Clwyd MP which found that many patients, families and staff members feel they cannot give feedback, raise concerns or make complaints for fear of the consequences.¹⁵⁷

154 NHS England (2013), *Transforming participation in health and care*.

155 National Advisory Group on the Safety of Patients in England (2013), *A promise to learn – a commitment to act: improving the safety of patients in England*.

156 Ibid.

157 Clwyd, A. and Hart, T. (2013), *Review of NHS Hospitals Complaints System: putting patients back in the picture*.

5

Making patient engagement a reality

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“Many of the initiatives that have been introduced in recent years at a national level have served as a “bolt on” to the system and have still to engender the culture change that is needed to harness the full part which patients can play.”

Putting patients at the heart of the NHS will be the only route to sustainable healthcare spending. New models of healthcare are already realising the hidden human capital of patients and communities to deliver more for less.¹⁵⁸ Successive governments have introduced reforms to put patients at the heart of the NHS. However while politicians, policymakers and professionals freely use the language of patient engagement and patient-centred care the reality does not match up. As a KPMG survey revealed, while 72 per cent of global health leaders believe empowered patients creates better value care, 89 per cent believe that health systems are designed around the needs of providers not patients.¹⁵⁹

There are a number of opportunities to accelerate this change and build on the advances that have already been made. Creating a patient-centred system requires a shift in the culture of patients, professionals, providers and commissioners. This depth of cultural change in an organisation as vast and as complex as the NHS will not be achieved quickly or through any single measure. Many of the initiatives that have been introduced in recent years at a national level have served as a “bolt on” to the system and have still to engender the culture change that is needed to harness the full part which patients can play.

Instead a paradigm shift is needed where patients, professionals and the system will behave in a totally different way. This cannot be achieved by the NHS alone. Continued advance of a patient-centred health system will require further use of outside expertise that has changed the face of industries such as retail through digital services and customer insight. Moreover, the spread of “expert patients” will also take place outside the publicly funded system. The NHS must learn to embrace patient engagement regardless of where it originates.

The future patient

Changing patient behaviour is key to reducing demand on the NHS. Encouraging patients to lead healthier lifestyles or becoming more involved in their care can lead to better outcomes and greater efficiency. However despite the evidence that patient involvement can underpin better healthcare, professionals and providers continue to see patients as “costs,” not potential “assets”. Patients are often the best judge of the quality of care they receive and how it could be organised more effectively, yet a culture of paternalism prevails in the NHS. While patients should indeed take greater responsibility for their health and care it is also important that the system supports this. “Bad decision-making” from patients often arises from the system continuing to be built around the interests of providers. For example, missed appointments to see a GP are partly a consequence of most primary care services only being available during working hours. Poor lifestyle choices are compounded by the absence of positive incentives or accessible advice and support. Exhorting people to change how they use the NHS will only go so far. Professionals, providers and the system must be aligned with the needs of patients to harness their vital contribution in delivering higher value healthcare.

The future professional

The “expert patient” must be a partner in their care not a passive recipient. Clinical professionals must nurture and value this partnership to make patient engagement a reality. While doctors have recognised the importance of patient involvement, the traditional culture of “doctor knows best” still prevails.¹⁶⁰ Doctors hold the balance of power in a patient consultation and are still trained to solve problems, not to help patients build the confidence and ability to manage their conditions. Indeed, doctors

¹⁵⁸ International Partnership for Innovative Healthcare Delivery (2012), *A neglected resource: Transforming healthcare through human capital*.

¹⁵⁹ Britnell, M. (2014), “Integration and patient power”, Presentation given at *Reform* conference, 1 July.

¹⁶⁰ Health Foundation (2010), “The patient will see you now”, *Health Service Journal*.

“Exhorting people to change how they use the NHS will only go so far.”

“A patient and consumer friendly approach to medicine needs to be prioritised throughout the working lives of professionals.”

often feel patients are not “emotionally ready or willing to participate” and often argue they cannot “make time” to engage patients in shared decision-making.¹⁶¹ As the King’s Fund has argued, doctors often fail to consider what patients want as they “simply do not view diagnosing patient preferences as an important part of their work”.¹⁶² Professionals also need to be prepared to put the customer first. Despite the change in expectations amongst the public there continues to be a resistance from professionals in viewing patients as customers at all.

There is no quick fix for transforming professional cultures however there is far greater scope to incorporate patient engagement and customer experience into clinical training. Training curricula remain outdated in the face of rising patient expectations and the need for effective self-management to combat the tide of chronic disease.¹⁶³ As a World Health Organisation report argued, “the success of the health care workforce and health care organisations depends upon the extent to which they can focus care on using the patients’ perspective to increase their engagement in continuing and/or adopting behaviours that best promote health and delay complications related to chronic conditions”.¹⁶⁴ The skills to support patients to change behaviours and lifestyle choices are more important than ever. Clinicians must be able to communicate with patients in a way which both elicits information and builds confidence is key. This means acknowledging a patient’s own expertise and their priorities.¹⁶⁵ The *Shape of Training* Review recommended that patients be involved in the training and examination of clinicians to help professionals gain a patient perspective.¹⁶⁶

However ensuring clinicians are ready and able to support patients as partners in care or to consider the patient perspective cannot be achieved through a limited number of teaching modules during pre-registration training alone. A patient and consumer friendly approach to medicine needs to be prioritised throughout the working lives of professionals. Providers should ensure that all clinicians receive continuing professional development in customer experience and patient involvement. Some hospitals are already working with private sector brands to train staff in how to deliver better customer service. Individual doctors and nurses should also be performance managed for their ability and willingness to engage with patients and customers. Front line staff should be held to account for customer experience in same way that hospital leadership is. Demonstrating these values should become a key part of staff appraisal.

The future NHS

A patient-centred NHS

Despite the enthusiasm for putting the patient first at a national level the NHS continues to largely behave as a “provider-centric” system. Local Involvement Networks (LINKs) and now HealthWatch sought to create greater local accountability. Patient representatives on CCGs and Foundation Trust Governors also aimed to bring lay perspectives into the decision making process for NHS organisations. Yet rather than giving the patient a clear voice, they remain on the margin of debate compared to the voice of the provider. Similarly the NHS Constitution has still had minimal impact on creating a culture of patient rights. Personal health budgets are still in their infancy and have been rolled out very cautiously despite their potential to transform health and care.

Of all the reforms of the last decade patient choice had the greatest potential to create people-centred care. However choice has been grafted onto the NHS without providers

¹⁶¹ Coulter, A. (2009), *Implementing shared decision making in the UK*, Health Foundation. Also see, da Silva, D. et al. (2011), *Helping people help themselves*, Health Foundation.

¹⁶² Mulley, A. et al. (2012), *Patients’ preferences matter: Stop the silent misdiagnosis*, King’s Fund.

¹⁶³ Bhutta, Z. et al. (2010), “Education of health professionals for the 21st century: a global independent Commission”, *The Lancet*, Vol. 375, Issue. 9721; Frenk, J. et al. (2010), “Health professionals for a new century: transforming education to strengthen health systems in an independent world”, *The Lancet*, Vol. 376, Issue. 9756.

¹⁶⁴ World Health Organisation (2005), *Preparing a health care workforce for the 21st century*.

¹⁶⁵ Hogg, C. (2004), “Patient-centred care – tomorrow’s doctors”, General Medical Council.

¹⁶⁶ Greenaway, D. (2013), *Securing the future of excellent patient care*.

“Despite the enthusiasm for putting the patient first at a national level the NHS continues to largely behave as a “provider-centric” system.”

“Currently there are few incentives for commissioners to fund patient involvement programmes even though they have a clear return on investment.”

embracing a consumer mentality. Despite national expectation that all GPs should be giving patients a choice of provider at referral, in a reality less than half of patients recall being offered such a choice.¹⁶⁷ While this Government introduced a “choice mandate” following the passage of the 2012 Health and Care Act, since then national organisations, including NHS England and Monitor, have not effectively worked in partnership to ensure more patients are offered choice. For much of the NHS offering or responding to “choice” is not a priority.¹⁶⁸ Few NHS providers act as if they were in a competitive market place where patients regularly make choices on where to receive their care. While the last Government measured the performance of GPs offering choice since 2010, the National Patient Choice Survey has been discontinued.

Despite the growing enthusiasm for shared decision-making and greater patient involvement in clinical care itself, these tools and techniques remain a bolt onto a system that continues to see patients as passive bystanders. Embedding these ideas into clinical practice requires a fundamental shift in the culture of the system and the priorities of commissioners. These programmes continue to be funded through separate and specific budgets, alongside rather than instead of traditional services. Harnessing the patient contribution has the potential to substitute traditional services and maximising the impact of the patient will require disinvestment in the existing provider centred infrastructure of the NHS. Currently there are few incentives for commissioners to fund patient involvement programmes even though they have a clear return on investment.

A consumer friendly NHS

The NHS Outcomes Framework and NHS England’s Mandate has made “ensuring people have a positive experience of care” a key priority for the NHS.¹⁶⁹ To date the focus has been on measuring patient experience. However despite the political enthusiasm for the Friends and Family Test the initiative has proved controversial in the NHS and there are number of signs that NHS organisations have not embraced this measure of patient experience.¹⁷⁰ Providers are only just starting to learn from patient feedback to improve their offer to customers. Speaking at a *Reform* seminar in 2013 Neil Churchill, the National Director of Patient Experience, warned there is a danger that providers will “comply” with the national emphasis on patient experience instead of “owning” the direction of travel to become “a listening organisation, a learning organisation centred on patients”.¹⁷¹

“If patient feedback is to have a real impact then it cannot be the business of management alone.”

While there is a long experience of using patient surveys in hospitals these are not always designed to capture data that will help providers understand what their customers want and improve their service. Hospitals are still far behind private sector organisations in capturing relevant, real time data and acting on it immediately. While some providers have introduced “Directors of Patient Experience” to lead improvement efforts, for example, they rarely sit at board level. If patient feedback is to have a real impact then it cannot be the business of management alone. Leading providers are engaging front line staff in efforts to understand what patients want, some collaborating with private sector organisations, and in particular retailers, to give staff effective continuing professional development in customer service.¹⁷² All NHS organisations should go further to harness private sector and third sector expertise in customer service and understanding the values and needs of patients.

¹⁶⁷ *Health Service Journal* (2014), “Progress on choice of provider has stalled, figures show”, 21 August.

¹⁶⁸ *Health Service Journal* (2012), “CCG leaders favour integration over competition”, 8 November.

¹⁶⁹ Department of Health (2013), *The NHS Outcomes Framework 2014/15*; Department of Health (2013), *The Mandate: A mandate from the Government to NHS England: April 2014 to 2015*.

¹⁷⁰ *Health Service Journal* (2013), “NHS England reviews ‘friends and family’”, 26 November

¹⁷¹ Cawston, T. (ed.) (2013), *Patient-centred care, Reform*.

¹⁷² *Ibid.*

“Many other industries, such as banking, retail and tourism, have transformed the delivery of their goods or services towards more consumer friendly approaches which harness the contribution of the customer.”

Outside the acute sector, progress is even worse. Primary care remains a cottage industry without the capacity or resources to introduce effective customer feedback mechanisms. Commissioners need to invest greater effort in measuring the patient experience to better understand the needs and expectations of the populations they serve. Harnessing these insights can allow healthcare organisations to better organise their services to meet these needs. For example, understanding patient values and motivations can allow practitioners to give better advice to patients in encouraging uptake and adherence to medication.¹⁷³

Learning from outside the NHS

The NHS has been comparatively slow to engage the consumer in the delivery of health and care services. Many other industries, such as banking, retail and tourism, have transformed the delivery of their goods or services towards more consumer friendly approaches which harness the contribution of the customer. This has particularly occurred through the use of technology to create convenient, mobile services and increase productivity dramatically by tapping into the consumer as a co-producer of the service.

Personal online and mobile banking has been pivotal in this transformation of consumer engagement. In the banking industry, around 50 per cent of internet users now use online banking in the UK. This enabled a reduction in UK bank branches of 40 per cent between 1983 and 2013.¹⁷⁴ In the same way the travel industry has adapted to enable consumers to book holidays online, with 50 per cent of internet users using the internet for travel or travel related accommodation.¹⁷⁵ This allowed for a net fall of 1,779 travel agent shops in 2013 alone.¹⁷⁶ In the retail industry more broadly over 10 per cent of all retail sales are now made over the internet, with 27 per cent made on a mobile device.¹⁷⁷

“...while there have been recent initiatives to improve “patient engagement” in advanced health systems, low and middle income countries have long been harnessing the role of the patient and their family in improving value.”

As Paul Corrigan has argued, the evolution of retail also offers lessons for the NHS. In recent decades grocery retail has developed away from high cost, fragmented, high street-based shops into supermarkets that offer greater value, choice and convenience for consumers and which harness the shopper’s own labour capacity. Retail chains have changed the way they do business to meet the needs of their consumer and better harness their value whether through online shopping, self-service checkouts or loyalty cards to harness customer insight and target promotions to improve customer satisfaction.¹⁷⁸ Similar efforts to extend transparency and feedback have changed the face of a number of industries. Price comparison sites and rating sites like Tripadvisor have given consumers far more meaningful and informed choices between products and services, often shaped by peer review.

As past *Reform* work has demonstrated, while there have been recent initiatives to improve “patient engagement” in advanced health systems, low and middle income countries have long been harnessing the role of the patient and their family in improving value.¹⁷⁹ The shortage of trained medical professionals has meant that providers must harness all sources of human capital, including patients and communities.¹⁸⁰

The constant information revolution

Important progress has been made in improving access to health information and improving transparency in the NHS. Technology advances and a determination from the centre to harness “open data” has meant that there is now a wealth of information

173 Ibid.

174 ONS (2013), *Internet Access – Households and Individuals.*; BBC News (2014), “Mobile phone banking transactions double in a year, BBA says.” 31 March.

175 ONS (2013), *Internet Access – Households and Individuals.*

176 Tweedy, J. (2013), “Mary Portas can’t save travel agent stores; the high street is dead, says holiday boss”, *Daily Mail*.

177 ONS (2013), *Retail Sales, October 2013.*

178 Corrigan, P. (2014), *Going with change, Reform.*

179 Cawston, T. et al. (2012), *Healthy competition, Reform; Reform (2013), Healthy innovation.*

180 Dzau, V. et al. (2012), *A Neglected Resource: Transforming Healthcare Through Human Capital*, The Global Health Policy Summit.

“While technology has transformed the experience of consumers in other sectors the NHS has made only limited progress in exploiting the potential of social media and smart phones.”

available to patients and the public.¹⁸¹ There has been constant growth in the number of people using NHS Choices and other online platforms. Yet while technology has transformed the experience of consumers in other sectors the NHS has made only limited progress in exploiting the potential of social media and smart phones. The NHS has made progress in releasing data and giving patients access to their health records but the pace of change has been surpassed by public expectations.

By contrast there is now rapid advances in consumer facing technology outside the NHS. A significant and growing number of patients are independently using smart phone Apps to support their health and wellbeing. Providers of these technologies are often targeting the consumer directly rather than attempting to get the NHS to purchase their services. Insurers and employers are also seeking to provide greater access to online and remote healthcare that is not typically offered by the NHS. For example, in 2014 a new application called Babylon offered consumers access to a “virtual health service”.¹⁸² Social networking sites such as IWantGreatCare and PatientsLikeMe have developed outside the traditional health system. It is quite possible the technology enabled “expert patient” will emerge more quickly outside the NHS than from within. This in turn will increase the expectation among NHS patients to be able to access the same form of technologies.

Making patient engagement a reality

This Parliament has seen progress made and continuing to measure patient experience and accelerating the rollout of personal budgets will lead to further improvement. However policymakers should go further to ensure the whole system makes the patient the priority. Measuring choice at a national level and holding commissioners to account for ensuring patients are offered a choice by GPs at a referral could revive choice as a priority for the NHS.

“It is quite possible the technology enabled “expert patient” will emerge more quickly outside the NHS than from within.”

NHS providers and commissioners should be expected to appoint a “Director of Patient Experience” at board level. While many NHS organisations now have mechanisms to capture patient input and insight in service development, the voice of the patient can still be a marginal voice. As well as measuring patient experience the NHS should also be looking to measure levels of patient activation and involvement. It should be for healthcare organisations and their Boards to develop measures and plans to drive patient engagement.

Industries such as retail have already undergone this journey. They have used digital services and customer insight to transform services around the consumer to improve experience and harness their contribution. The NHS should look to draw on this outside expertise to continue to advance a patient-centred health system. As “expert patients” emerge outside the publicly funded system, the NHS must learn to embrace patient engagement regardless of where it originates.

181 Kesley, T. (2014), Speech to NHS Confederation, 6 June.

182 *Health Service Journal* (2014), “Parsa launches new ‘virtual health service’ app”, 28 April.

Annex: Wanless Review scenarios

Table 5: Breakdown of cost drivers under the Wanless engagement scenarios

Source: Wanless, D. (2002), *Securing our future health*

	Solid progress	Slow uptake	Fully engaged
Changes in demand for care			
UK life expectancy at birth by 2022	Men: 80.0, Women: 83.8	Men: 78.7, Women: 83.0	Men: 81.6, Women: 85.5
Ill health among the elderly	No change of rates of long term ill health. 5% fall in demand for acute care by 2022.	Increase in long-term ill health (age-specific rates of physical dependency increase by 1% a year). 10% rise in demand for acute care by 2022	Healthy life expectancy increases broadly in line with life expectancy. 10% reduction in demand for acute care by 2022
Health promotion	Current public health targets met, leading to reductions in hospital admissions and GP visits. Health promotion expenditure grows in line with expenditure on GP and hospital care	No change in public health measures. Health promotion expenditure grows in line with population growth and inflation	Progress beyond current public health targets – leading to greater reductions in hospital admissions and GP visits – combined with higher spending on health promotion. Health promotion expenditure grows in line with GP and hospital care, plus an additional £250 million a year by 2007-08
Smoking	Below 24% of adults and less than 15% of pregnant women	Prevalence of smoking remains the same	Prevalence of smoking achieves solid progress reduction ahead of target and then reduces further
Obesity	Below 8% for women, 6% for men	Levels of obesity remain the same	Trends in obesity achieve solid progress aims ahead of target and then continue further
Health seeking behaviour 15-64 year olds	10% reduction in hospital admissions, GP visits and prescriptions related to coronary heart disease and stroke for 15-64 year olds. 5% reduction in all other hospital admissions, GP visits and prescriptions for 15-64 year olds	No change	25% reduction in hospital admissions, GP visits and prescriptions for 15-64 year olds. 15% reduction in all other hospital admissions, GP visits and prescriptions for 15-64 year olds

Health seeking behaviour among the elderly	By 2022, hospital and GP care use per head among over 75s matches current patterns of use among 65-74 year olds. One additional GP visit per person per year on average by 2022	No change	By 2022, hospital and GP care use per head among over 75s matches current patterns of use among 65-74 year olds. One additional GP visit per person per year on average by 2022
Self care	Switch of 1% of GP activity to pharmacists; reduction of 17% in outpatient attendances among 225,000 people using self-care. Higher patient expectations	Switch of 1% of GP activity to pharmacists; reduction of 17% in outpatient attendances among 225,000 people using self-care. No change in patient expectations	Switch of 2% of GP activity to pharmacists; reduction of 17% in outpatient attendances among 450,000 people using self-care (result of a step-change in public engagement). Dramatic improvement in public engagement via ICT

Changes in the delivery of care

Medical technology	Contributes around 3 percentage points a year to growth in health spending	Contributes around 2 percentage points a year to growth in health spending	Contributes around 3 percentage points a year to growth in health spending
ICT	Spending doubles in real terms by 2003-04	Spending doubles in real terms by 2007-08	Spending doubles in real terms by 2003-04
Productivity growth	Increases from 2 to 2½ % a year in the first decade to 3% a year in the second	Increases from 1½ % a year in the first decade to 1¾ % a year in the second	Increases from 2 to 2½% a year in the first decade to 3% a year in the second

Bibliography

Accenture (2013), *Consumer Survey of Patient Engagement Recap*.

Agency for Healthcare Research and Quality, *Health Literacy Interventions and Outcomes: An updated systematic review*, No. 199.

Ahmed, S. et. Al (2013), "Innovations in e-health", *Quality of Life Research*.

Alakeson, V. and Rumbold, B. (2013), *Personal health budgets: Challenges for commissioners and policy-makers*, Nuffield Trust.

Allen, J. (2009), "If You Build It, Will They Come? The Kaiser Permanente Model of Online Health Care", *Health Affairs*.

Allender et al. (2009), "The burden of smoking-related ill health in the UK", *British Medical Journal*, vol. 18.

Alzheimer's Society (2014), *Dementia UK: Update*.

Baer, D. (2011), "Patient-physician e-mail communication: the Kaiser Permanente experience", *Journal of Oncology Practice*, vol.7 no.4.

Barber, N. et al. (2003), "Patients' problems with new medication for chronic conditions", *British Medical Journal*.

BBC News (2014), "Mobile phone banking transactions double in a year, BBA says," 31 March.

Bhutta, Z. et al. (2010), "Education of health professionals for the 21st century: a global independent commission", *The Lancet*, vol. 375, issue 9721.

Blunt, I. (2013), *Trends in emergency admissions for ambulatory care sensitive conditions, 2001 to 2013*, Nuffield Trust and Health Foundation.

Bostock, S. and Steptoe, A. (2012), "Association between low functional health literacy and mortality in older adults: longitudinal cohort study", *British Medical Journal*.

Boyle, D. (2013), *The barriers to choice review*.

Britnell, M. (2014), "Integration and patient power", Presentation given at *Reform* conference, 1 July.

Bunt, L. and Harris, M (2009), *The human factor*, Nesta.

Bupa (2012), *Patient Power*.

Campbell, D. (2014), "NHS chief announces plan to give patients cash to fund their own care", *The Guardian*, Tuesday 8 July.

Care Quality Commission (2013), *National findings from the 2013 Inpatients Survey*.

Carers UK, Circle and University of Leeds (2011), *Valuing Carers 2011*.

Cawston, T. (ed.) (2013), *Patient-centred care, Reform*.

Cawston, T. et al. (2012), *Healthy competition, Reform*.

Chen, C. et al. (2009), "The Kaiser Permanente Electronic Health Record: transforming and streamlining modalities of care", *Health Affairs*, vol.28 no.2.

Clwyd, A. and T. Hart (2013), *A Review of the NHS Hospitals Complaints System: Putting Patients Back in the Picture*, Department of Health.

Corrie, C. (ed.) (2014), *Disruptive innovation in public service reform, Reform*.

- Corrigan, P. and Parish, M. (2014), *Going with change*.
- Coulter A. and Ellins J. (2007), "Effectiveness of strategies for education, and involving patients", *British Medical Journal*, vol. 335, p.26.
- Coulter et al. (2011), *Making shared decision-making a reality*, King's Fund.
- Coulter, A. (2009), *Implementing shared decision making in the UK*, The Health Foundation.
- Da Silva, D. et al. (2011), *Helping people help themselves*, The Health Foundation.
- Department of Health (2000), *The NHS Plan: a plan for investment, a plan for reform*.
- Department of Health (2003), *Building on the Best: Choice, Responsiveness and Equity in the NHS*.
- Department of Health (2004), *Choice, responsiveness and equity national consultation public survey*.
- Department of Health (2004), *Choosing health: making healthy choices easier*.
- Department of Health (2005), *Public Attitudes to Self Care Baseline Survey*.
- Department of Health (2007), *Research evidence on the effectiveness of self care support*.
- Department of Health (2010), *Equity and excellence: Liberating the NHS*.
- Department of Health (2011), *NHS Future Forum*.
- Department of Health (2012), "More choice in mental health", press release, 13 December.
- Department of Health (2012), *Liberating the NHS: No decision about me, without me, Government response*.
- Department of Health (2012), *Long term conditions compendium of information*.
- Department of Health (2012), *Report on the effect of the NHS Constitution*.
- Department of Health (2012), *The power of information*.
- Department of Health (2013), "£1 billion to help A&Es and NHS staff access medical records in hi-tech hospital revolution", press release, 4 September.
- Department of Health (2013), News release: Reducing obesity and improving diet, 25 March 2013
- Department of Health (2013), *The Mandate: A mandate from the Government to NHS England: April 2014 to 2015*.
- Department of Health (2013), *The NHS Outcomes Framework 2014/15*.
- Discovery Vitality (2014), *Do Well*.
- Dixon-Fyle, S. and Kowallik, T. (2010), *Engaging consumers to manage health care demand*, McKinsey & Company.
- Donnelly, L. et al (2007), "Adherence to insulin and its association with glycaemic control in patients with type 2 diabetes", *QJM*.
- Dzau, V. et al. (2012), *A Neglected Resource: Transforming Healthcare Through Human Capital*, The Global Health Policy Summit.
- Ellins, J. (2005), *How engaged are people in their health care? Findings of a national telephone survey*, Health Foundation.
- Emont, S. (2011), *Measuring the impact of patient portals: what the literature tells us*,

California Healthcare Foundation.

European Health and Fitness Association (2013), *The 2013 State of the UK Fitness Industry Report*.

Expert Advisory Group (2014), *Next steps for the NHS Constitution*.

Foot, C. et al (2014), *People in control of their own health and care*, King's Fund.

Fox, A. (2012), *Personalisation: lessons from social care*, RSA.

Frenk, J. et al. (2010), "Health professionals for a new century: transforming education to strengthen health systems in an independent world", *The Lancet*, Vol. 376, Issue. 9756.

Future Forum Working Group (2012), Letter to the Secretary of State for Health from the NHS Future Forum working group on the NHS Constitution.

Greenaway, D. (2013), *Securing the future of excellent patient care*.

Greene J. et al. (2013), "When seeing the same physician, highly activated patient have better care experience than less activated patients", *Health Affairs*, vol. 32, no. 7.

Greene, J et al. (2012), *Why does patient activation matter*, The Commonwealth Fund.

Health Foundation (2010), *The patient will see you now*.

Health Foundation (2011), *Helping people help themselves*.

Health Foundation (2012), *Helping people share decision-making*.

Health Select Committee (2010), *Public expenditure*.

Health Select Committee (2010), *Responsibilities of the Secretary of State for Health: Minutes of evidence*.

Health Select Committee (2012), *Public expenditure*.

Health Service Journal (2012), "CCG leaders favour integration over competition", 8 November.

Health Service Journal (2013), "NHS England reviews 'friends and family'", 26 November.

Health Service Journal (2014), "Parsa launches new 'virtual health service' app", 28 April.

Health Service Journal (2014), "Progress on choice of provider has stalled, figures show", 21 August.

Healthcare UK (2014), *Digital health: working in partnership*.

HealthWatch (2014), "Nearly a fifth confess to knowingly using A&E for non-emergencies", 4 March.

Hex, C. et al (2012), "Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs", *Health Economics*.

Hibbard, J. et al. (2009), "The Development and Testing of a Measure Assessing Clinician Beliefs About Patient Self-Management", *Health Expectations*, vol.13.

HM Government (2010), *Healthy lives, healthy people*.

Hogg, C. (2004), "Patient-centred care – tomorrow's doctors", General Medical Council.

- Horne et al. (2012), *People powered health: Health for people, by people and with people*, Nesta.
- House of Lords Select Committee on Public Service and Demographic Change (2013), *Ready for ageing?*.
- HSCIC (2012), *Health survey for England 2012*.
- Iacobucci, G. (2010), "Fifth of appointments wasted on 'worried well', leading GPs warn", *Pulse*, 16 March.
- ICM Research (2013), *Fear of raising concerns about care: A research report for the Care Quality Commission*.
- Illman, J. (2013), "CCG tenders integrated older people's service worth up to £1 billion", *Health Service Journal*.
- IMF (2010), *Macro Fiscal Implications of Health Care Reform in Advanced and Emerging Economies*.
- Institute for Health Policy (2012), *Kaiser Permanente Policy Story: Engaging patients online with My Health Manager*.
- International Partnership for Innovative Healthcare Delivery (2012), *A neglected resource: Transforming healthcare through human capital*.
- Ipsos MORI (2013), *The GP Patient Survey: Summary Report*.
- Kaiser Permanente, "About us: total health connectivity".
- Kesley, T. (2014), Speech to NHS Confederation, 6 June.
- KPMG (2014), *Creating new value with patients, carers and communities*.
- Liddell, A. et al. (2008), *Technology in the NHS: Transforming the patient's experience of care*, King's Fund.
- Maisonneuve, C. and Martins, J. (2013), *Public spending on health and long term care: A new set of projections*, OECD.
- McCarthy, D. (2009), *Kaiser Permanente: Bridging the quality divide with integrated practice, group accountability and health information technology*, The Commonwealth Fund.
- Monitor (2014), *NHS foundation trusts: quarterly report (quarter 1 2014/5)*.
- Mulley, A. et al. (2012), *Patients' preferences matter: Stop the silent misdiagnosis*, King's Fund.
- National Advisory Group on the Safety of Patients in England (2013), *A promise to learn – a commitment to act: improving the safety of patients in England*.
- National Audit Office (2012), *Progress in making NHS efficiency savings*.
- National Audit Office (2012), *The management of adult diabetes services in the NHS*.
- National Audit Office (2013), *Emergency admissions to hospital: managing the demand*.
- National Audit Office (2014), *Adult social care in England: overview*.
- National Information Board (2014), *Personalised health and care 2020*.
- National Voices (2012), *A narrative for person-centred coordinated care*.
- National Voices (2014), "Prioritising person-centred care – the evidence."
- Naylor, C. et al (2012), *Long-term conditions and mental health: the cost of co-morbidities*, King's Fund.

- NHS Choices (2014), "Home remedies for common conditions".
- NHS Confederation (2012), *Joint personal budgets: a new solution to the problem of integrated care?*
- NHS England (2012), *Personal health budgets pilot – final evaluation report*.
- NHS England (2013), "Up to 100,000 people to use the internet to improve their health", press release, 13 March.
- NHS England (2013), *Call to Action*.
- NHS England (2013), *NHS Planning Guidance December 2013*.
- NHS England (2013), *Transforming participation in health and care*.
- NHS England (2013), *Transforming urgent and emergency care services in England*.
- NHS England (2014), *Five Year Forward View*.
- NHS England (2014), *The Forward View into action: planning for 2015-16*.
- NHS England and Monitor (2013), *Populus summary: outpatient appointment referrals*.
- NHS Trust Development Authority (2014), *Paper E: NHS Trust Service and Financial Performance Report*, Board meeting, 18 September 2014.
- Nielsen-Bohman, L. et al. (2004), *Health literacy: A prescription to end confusion*, Institute of Medicine.
- Parker, R. et al. (2003), *Health literacy: a policy challenge for advancing high-quality health care*.
- Nossel, C. (2011), *The Vitality Wellness Programme: Experience from South Africa*, Discovery.
- Nunes, V. et al. (2009), *Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence*.
- O'Connor AM et al. (2007), "Toward the 'tipping point': decision aids and informed patient choice" *PubMed*, vol. 26, no. 3.
- Office for Budget Responsibility (2014), *Fiscal sustainability report*.
- ONS (2013), *Internet Access – Households and Individuals*.
- ONS (2013), *Retail Sales, October 2013*.
- ONS (2014), *Household Expenditure Estimates, 2013: Q4*.
- Øvretveit, J. (2011), *Does clinical coordination improve quality and save money? Volume 2*, Health Foundation
- Parliamentary and Health Service Ombudsman (2013), *Submission by the Health Service Ombudsman for England to the Review of the NHS Complaints System*.
- Patients Association (2012), *The NHS Constitution: Fact or Fiction?*
- PatientsLikeMe (2004), *Openness Philosophy*.
- Poteliakhoff, E. and J. Thompson (2011), *Data briefing – Emergency bed use: what the numbers tell us*, The King's Fund.
- Propriety Association of Great Britain, "Fast facts", accessed June 2014, <http://www.pagb.co.uk/media/facts.html>.
- Public Administration Select Committee (2014), *More complaints please!*
- Public Health England (2014), *New release: Obesity and Health*.

Reform (2013), *Healthy innovation*.

Richards, N. and Coulter, A. (2007), *Is the NHS becoming more patient-centred? Trends from the national surveys of NHS patients in England 2002-2007*.

Richmond Group (2010), *How to deliver high quality, patient-centred, cost-effective care*.

Roberts, A. et al. (2012), *A decade of austerity? The funding pressures facing the NHS from 2010/11 to 2021/22*, Nuffield Trust.

S. Gupta et al. (2011), "PatientsLikeMe: An online community of patients", *Harvard Business Review*.

Stacy et. al (2014), Decision aids for people facing health treatment or screening decisions, The Cochrane Collaboration, p.2.

Stevens, S. (2014), Speech by Simon Stevens, 1 April 2014.

Sullivan, R. et al (2009), *Economic burden of cancer across the European Union: a population-based cost analysis*.

The Commonwealth Fund (2012), *International perspectives on Patient Engagement: Results from the 2011 Commonwealth Fund Survey*.

The Economist (2011), "Getting on the treadmill", 8 October.

The Health Foundation (2010), *Personal health budgets: Research scan*.

The King's Fund (2014), *Quarterly Monitoring Report October 2014*.

The Self Care Forum, "What do we mean by self care and why is it good for people".

Tian, Y. et al. (2012), *Data briefing – Emergency hospital admissions for ambulatory care-sensitive conditions: identifying the potential for reductions*, King's Fund.

Todd, R. (2013), "2015 records access promise scaled back", *eHealth Insider*, 29 October.

Triggle, N. (2014), "A&E: Some patients visit units 50 times a year", BBC Online, 7 January.

Tweedy, J. (2013), "Mary Portas can't save travel agent stores; the high street is dead, says holiday boss", *Daily Mail*, 1 March.

Volpp, K. (2014), *The Case for Incentivising Health: Using behavioural economics to improve health and wellness*, AIA Australia.

Wanless, D. (2002), *Securing our Future Health: Taking a Long-Term View*.

Wanless, D. et al. (2007), *Our future health secured?*, King's Fund.

Wicks, P. and Hixon, J. (2013), "The Patient Engagement Pill: Lessons from Epilepsy", *Health Affairs*, February 7.

World Health Organisation (2005), *Preparing a health care workforce for the 21st century*.

Zhou, YY. et al. (2010), "Improved quality at Kaiser Permanente through e-mail between physicians and patients" in *Health Affairs*, vol. 29 no. 7.

Reform
45 Great Peter Street
London
SW1P 3LT

T 020 7799 6699
info@reform.uk
www.reform.uk

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