

# EDITORIALS

Editorials are usually commissioned. We are, however, happy to consider and peer review unsolicited editorials

See <http://resources.bmj.com/bmj/authors/types-of-article/editorials> for more details

**bmj.com** Read more *BMJ* articles about empowering patients <http://www.bmj.com/bmj-series/shared-decision-making>

## What will bring about the patient centred revolution?

We need to go beyond well meaning policies

**Paul Hodgkin** chief executive officer, Patient Opinion, Sheffield S3 9EN, UK

[paul.hodgkin@patientopinion.org.uk](mailto:paul.hodgkin@patientopinion.org.uk)

**Jeremy Taylor** chief executive officer, National Voices, London, UK

The incoming coalition government wasted no time in declaring its intention to “put patients at the heart of the NHS” in England. The 2010 white paper *Equity and Excellence: Liberating the NHS* promised more choice, control and information.<sup>1</sup> It also promised more shared decision making with “no decision about me without me” and a powerful new “consumer” champion Healthwatch to stand up for our interests. This government has continued a tradition of rhetorical lip service to the centrality of the patient and if anything has ramped up the rhetoric. “Putting patients first,” “patients first and foremost”—the patient friendly platitudes abound in every official document.

What does it all mean? Putting patients at the heart is partly about patients acting as equal and informed partners in decision making, in contrast to traditional medical paternalism. It is partly about patients as consumers of services, empowered through greater choice, better information, and the opportunity to give feedback and rate services. It is also about patients exercising their rights and responsibilities as citizens, as set out in the worthy but little known NHS Constitution. Those who advocate for people with long term conditions increasingly see patients as managers of their own health. Such patients need better information, help, and support to manage. Many patients will say it is about seeing the whole person rather than just the illness—about holistic, joined up care and the importance of compassion, respect, and dignity.

Putting patients first is thus a pick and mix menu from which decision makers can select according to taste. The notion of “patient and public engagement” provides cover for a range of behaviours and attitudes, from the tokenistic to the genuinely liberating. “Patients as consumers” has been a popular item on the menu under this and the previous government. “Patients as victims or potential victims of harm” has sadly become part of the story as a result of high profile failings of care, such as those seen in Mid Stafford NHS Trust and Winterbourne View. Patients

as partners, managers, and citizens—or indeed owners (“the NHS belongs to us all” says the NHS Constitution)—have had rather less of a look in.

The guidance on participation recently published by NHS England does not entirely transcend the conceptual muddle—for example, how to reconcile “participation” (patients and citizens in the tent) with “insight and feedback” (examining your customer at a distance).<sup>2</sup> Nevertheless, it is an excellent resource, probably the best official articulation to date of putting patients at the heart, and it bears close attention.

The fact that such guidance should be thought necessary speaks volumes about the fraught relationship between healthcare and the citizen. In other areas of life, society demands autonomy and responsibility of its citizens. In healthcare it is different. Perhaps because illness can be inherently disempowering, because the medical model of care continues to dominate, and because the NHS is free at the point of use, behaviours and practices often seem to reinforce the dependency and passivity of the patient.

So what is likely to make a difference in empowering patients in the coming years? We see three trends that could

be transformative, all of which come from outside mainstream medicine and which challenge it to a greater or lesser extent.

Firstly, the growing population of people with multiple long term conditions, disabilities, and frailty will demand a different model of care and support—a primarily social not medical model. Such a model should mobilise patients’ own resources and the resources of their families and communities to help them stay well and functioning. It should also integrate the capacity of carers, friends, neighbours, peer supporters, local authorities, the NHS, and the voluntary and community sector. Many of the ingredients for this alternative approach are already in place, and the endless financial squeeze on the public sector could make it irresistible.

Secondly, the slow march towards greater transparency about performance, with national

director for patients and information Tim Kelsey as its current lead tub thumper, will continue to shift power from an often secretive and defensive NHS towards citizens.

Thirdly, digital technologies could change everything. It is always instructive to follow the money. In the Connecting for Health decade the English NHS spent around £10bn (€11.9bn; \$16bn) on informatics. Meanwhile citizens were also busy investing in their own informatics—laptops, PCs, smart phones, broadband, and the rest. If we assume a modest spend of £400 a year across each of the 25 million households in the UK on this kit, then citizens spent £100bn over the same decade. While the NHS was in gridlock over what mega-system to buy, citizens were outspending it by an order of magnitude to

get everything that Steve Jobs could give them: information, connectivity, mapping, voice, you name it. Coming soon will be personalised genomics from companies like “23andMe,” the ability for patients to upload data—such as blood pressure—on to their medical record, and social media supported behaviour change.

Where will these trends take us? Medicalisation and mar-

ketisation could stymie moves to a more social and holistic model of care; transparency exposes inadequacy but does not itself generate the drive to overcome it. The digital revolution could empower or enslave the citizen. It is too early to tell. But two things stand out. Firstly the forces that are driving these shifts are much deeper than health policy. Secondly it is up to us—patients and professionals—to create the future, to make the very best we can of these opportunities.

**Competing interests:** PH is chief executive officer of Patient Opinion, a not for profit website, where patients, carers, and staff can share stories of care across the NHS. JT is chief executive officer of National Voices, a national coalition of charities in England, which works with decision makers in health and social care to strengthen the voices of patients and citizens.

**Provenance and peer review:** Commissioned; not externally peer reviewed.

References are in the version on [bmj.com](http://bmj.com).

Cite this as: *BMJ* 2013;347:f6701



Whatever you want it to mean



**bmj.com**

- Research: Cost effectiveness of telehealth for patients with long term conditions (*BMJ* 2013;346:f1035)
- Research: Implementation of self management support for long term conditions in routine primary care settings (*BMJ* 2013;346:f2882)
- Clinical review: Telehealthcare for long term conditions (*BMJ* 2011;342:d120)
- Education and debate: Rising to the challenge: will the NHS support people with long term conditions? (*BMJ* 2005;330:657)

## Looking beyond “the house of care” for long term conditions

Some patients are at risk of being left outside

**Graham Watt** professor of general practice, University of Glasgow, Glasgow G12 9LX, UK  
 graham.watt@glasgow.ac.uk

Spike Milligan once described the invention of a machine that did the work of two men. Unfortunately, it took three men to work it.<sup>1</sup> As populations age, multimorbidity accrues, budgets tighten, and inequalities in health widen; patients, practitioners, and health systems cannot afford multiple services that provide fragmented care. We shall need machines that do the work of two people but need only one person to work them.

With its intrinsic features of contact, coverage, continuity, flexibility, cumulative knowledge, and trust, general practice has the potential to deal with this challenge. It is the natural hub of local health systems, providing unconditional personalised continuity of care for all patients, whatever combinations of problems they have. But practices cannot do this on their own; they need a host of effective partnerships—with patients, other services, NHS managers, and community resources.<sup>2</sup>

In England, the “house of care” has been adopted as a central metaphor in plans for improving care for people with long term conditions.<sup>3</sup> The house of care is based on substantial pilot work in the care of people with diabetes and is summarised in a recent King’s Fund review. The system involves personalised care planning at the centre of a model of care that includes engaged and informed patients, healthcare professionals who are committed to partnership working, supportive organisational systems, and local commissioning plans.<sup>3</sup> Everyone is being challenged to think and act differently.

The ubiquitous challenge is multimorbidity. In only 14% of patients with diabetes is diabetes the only health problem. In the most deprived

10th of the population, 24% of patients with diabetes also have coronary heart disease, 28% take prescription analgesics for chronic pain, and 21% take regular antidepressants.<sup>4</sup> Yet, because of the flat distribution of GPs,<sup>5</sup> steep social gradients in ill health, and the inverse care law that ensues,<sup>6</sup> patients with mental health problems in deprived areas have shorter consultation times and report less enablement as a result of seeing their GP.<sup>7</sup> Universal coverage is essential but not sufficient; practitioners also need to be able to respond proportionately to the problems that patients present.

Effective healthcare reduces the severity of health problems and delays their progression, while enabling patients to live well and independently.<sup>8</sup> Although the origins of health inequalities lie outside the health service, the inverse care law exacerbates them. If “tackling health inequalities is a central aim of the house of care,”<sup>9</sup> it will have to be more specific on this problem.

Self management by patients involves a spectrum of activity. Many patients already self manage, leading long lives without needing extra help from health professionals. For many others—especially in deprived areas—self management is a distant aspiration, rather than a starting point. This is because patients may lack the knowledge, motivation, and agency to behave in this way. They may also have a more complex task—

accessing multiple professions and services for different health and social problems. Will longer appointment times for all, to support self management in articulate well informed patients, use up NHS resources that could be better deployed?

The house of care is currently an aspiration,<sup>3</sup> with few examples of all its components in action. However, in another King’s Fund report, the active ingredients of coordinated care have

been described, including schemes for palliative care at home, mental health services, home care for people with dementia, care for older and frail people, and complex case management to reduce unnecessary hospital admissions.<sup>9</sup>

The report questions the need for defined care packages, arguing that protocol driven approaches lack the flexibility that patients with complex needs require. Such schemes are weaker without GP engagement, knowledge, and leadership. Bottom-up approaches are needed to develop “the building blocks of effective partnership working,” rather than “top-down approaches, no matter how well they may have worked elsewhere.”<sup>9</sup> Most of the projects took six to seven years to achieve the desired changes.

Key elements in building the house of care will be professional and organisational relationships. Co-production, or partnership working,<sup>10</sup> to achieve long term aims is not just a prescription for patients and practitioners. It is also needed, and is often less evident in terms of mutuality and trust, in the relationships between professional groups, services, and leaders at the top and bottom of health systems. At every level we need to conserve, build, monitor, and apply social capital.

Whereas previously doctors used to “listen to the patient, he is telling you the diagnosis,” increasingly they will “listen to the patient, she is telling you her treatment goals.”<sup>11</sup> In general, what matters to patients with multiple problems is functional status and social participation, rather than clinical or health service targets,<sup>12</sup> so the goals of care—how success and failure are judged, and by whom—are changing.

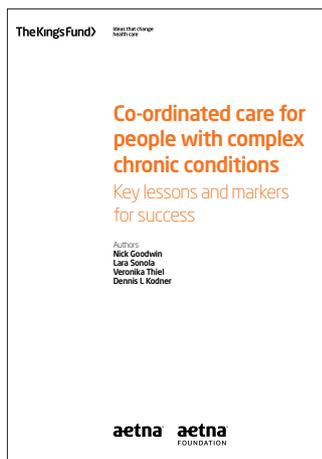
Whatever national and local arrangements are established to tackle these challenges, the product will be a compendium of individual narratives that reflect patients’ knowledge and confidence in living with their conditions and using services. In each of the four countries of the United Kingdom, random samples of patient experience will be needed to assess what is being achieved, and for whom.

Competing interests: None declared.

Provenance and peer review: Commissioned; not externally peer reviewed.

References are in the version on [bmj.com](http://bmj.com).

Cite this as: *BMJ* 2013;347:f6902



**What matters to patients with multiple problems is functional status and social participation, rather than clinical or health service targets**

## The development of executive functioning can be facilitated and compromised by the social, physical, and economic environments in which children are raised

### Breadlines, brains, and behaviour

Targeting executive functioning may help to loosen the link between demography and destiny

**Theresa M Marteau** director, Behaviour and Health Research Unit, University of Cambridge, Cambridge CB2 0SR, UK

**Peter A Hall** associate professor, Faculty of Applied Health Sciences, University of Waterloo, Waterloo, ON, Canada

The first annual report of the Commission on Social Mobility and Child Poverty published last month notes that the number of children starting life in poverty in the United Kingdom is high and increasing.<sup>1</sup> Given the links between poverty, brain development, and behaviour, these children start life with a higher chance than their more fortunate peers of behaving in ways that will harm their health and reduce their life expectancy. An understanding of these links offers some novel targets for intervention.

Evidence is emerging that our capacity to resist environments that tempt us (often without awareness) to overeat, smoke, drink excessively, or be physically inactive is influenced by the strength of our “executive functioning.” This is a theorised control network linked to the prefrontal cortex that regulates behaviour and thought.<sup>2</sup> Its core functions include inhibition of impulsive responses and focused attention. The strength of this behavioural control network is increasingly linked to environments in the early years of development, particularly poverty.<sup>3</sup> This association probably contributes to higher rates of smoking, drinking, poor diet, and physical inactivity in more deprived populations. In turn, the social clustering of these behaviours can explain most of the difference in life expectancy between the least and the most deprived sections of society.<sup>4</sup>

When measured early in childhood, executive functioning predicts a range of important life outcomes, including health and wealth. Some of the strongest evidence comes from the Dunedin study of all children born in this city in one year, who were followed for 32 years. Self control—measured in various ways between the ages of 3 and 11 years—independently predicted smoking at age 15, alcohol use, body mass index, and a range of other health indices measured in adolescence and adulthood.<sup>5</sup> The causal nature of these associations is strengthened by recent experimental laboratory studies.<sup>6</sup> Such findings do not of course preclude bidirectional associations between executive functioning and behaviour. Executive functioning and health related behav-



**Training their inner executives**

our seem to be linked by positive and negative feedback loops, such that those starting life with the strongest executive functioning are those who are more likely to engage in the behaviours that most nurture this brain system as well as longer term health.<sup>7</sup>

The development of executive functioning can be facilitated and compromised by the social, physical, and economic environments in which children are raised. This is illustrated in a recent longitudinal study of children in low income families in North Carolina, United States, who were followed from birth.<sup>4</sup> For each of the first four years of life that these children spent living below the poverty threshold, aspects of their executive functioning were correspondingly reduced. The mechanisms by which poverty influences brain development are hypothesised to involve two sets of variables: those relating to the physiological effects of chronic stress caused by low income, and those relating to parents’ ability to invest in goods and services that facilitate child development.<sup>4</sup> <sup>8</sup> Exposure to poverty does not affect all children equally, and the effects are predicted in part by genetically based predispositions.

Executive function continues to develop throughout and beyond childhood, with converging lines of evidence suggesting considerable plasticity in the prefrontal cortex that provides the scientific basis for interventions that target the brain. Two key targets for intervention in childhood and beyond are the brain and the environment.

There is great interest in whether the structure and function of brain circuits can be changed to optimise the operation of the executive control system. There are a few promising leads, outlined below in order of weight of supporting evidence. Firstly, aerobic exercise training can influence

the function, output, and even the structure of systems that support executive processes across the lifespan, with some studies documenting predicted improvements in academic performance.<sup>7</sup> <sup>9</sup> Secondly, the use of computer based brain training protocols shows promise, with some studies documenting convincing transfer of training to untrained domains of cognitive function.<sup>10</sup>

Thirdly, early intervention parenting programmes provide some evidence of improved cognitive functioning.<sup>11</sup> A less direct route to targeting executive functioning involves supplementing the incomes of the poorest families. This is estimated to improve cognitive function by similar amounts to that achieved by equivalent spending on early intervention programmes, but with additional benefits that accrue from increasing the incomes of the poorest families.<sup>8</sup>

A second key target for interventions that could reduce the behavioural and health consequences of suboptimal executive functioning is the environment. Changes made to behavioural cues in the environment can alter behaviour without drawing on executive functioning.<sup>12</sup> Unhelpful cues include the ready availability of fast food and alcohol, which prompt consumption, and helpful ones include the layout of public spaces that prompt walking. The removal of cues for unhealthier behaviours and the addition of ones for healthier behaviours has the potential to shape the behaviour of all those exposed, regardless of their executive functioning. Although plausible, this potential is untested.

Together with interventions that target brains, those that target environments could reduce the double hit faced by those born into poverty: living in environments that contain more cues for unhealthier behaviours, coupled with a reduced capacity to inhibit responses to those cues.

Although the number of children born into poverty in the UK and elsewhere is high and may be rising, a broadening array of findings from brain and behavioural sciences suggest novel targets for intervention to reduce the strength of association between “demography and destiny.”<sup>11</sup>

Competing interests: None declared.

Provenance and peer review: Commissioned; not externally peer reviewed.

References are in the version on [bmj.com](http://bmj.com).

Cite this as: *BMJ* 2013;347:f6750

**Propensity score matching is meant to mimic the balanced groups obtained by randomisation and allow an unbiased comparison of the true effect of treatment**

## Can joint replacement reduce cardiovascular risk?

Propensity score matching and landmark analysis were used to find out

**Mohammad Ehsanul Karim** PhD candidate, Department of Statistics, University of British Columbia, Vancouver, BC, Canada V6T 1Z4  
ehsan@stat.ubc.ca

Randomised trials are usually the best way to evaluate treatments, but observational designs can also provide useful insights into the effects of a particular treatment, as long as researchers use the appropriate statistical tools to help overcome the limitations of these studies. The paper by Ravi and colleagues,<sup>1</sup> which reported an association between total joint arthroplasty and a reduced risk of serious cardiovascular events over a median follow-up of seven years, is a good illustration of two of these techniques: propensity score matching<sup>2</sup> and landmark analysis.<sup>3</sup>

Patients are not randomised in observational comparative effectiveness studies. Lack of randomisation may contribute to differences in baseline characteristics of treated and untreated patients, including important prognostic factors such as age, sex, and comorbidities. Techniques such as propensity score matching make it possible to iron out these differences, so meaningful comparisons between treated and untreated groups can be made. The score, which is derived using multivariate logistic regression, defines each patient's "propensity" for treatment—in this case total joint replacement—on the basis of their measured characteristics, so researchers can compare similar patients who did and did not have treatment.

Propensity score matching is meant to mimic the balanced groups obtained by randomisation and allow an unbiased comparison of the true effect of treatment. Propensity scores are derived from characteristics that researchers can see and record, but they inevitably exclude unobserved patient characteristics that might still affect the outcome. Ravi and colleagues mentioned physical activity levels and use of cardioprotective drug treatments as two examples of unobserved and unrecorded factors that might confound the association between joint arthroplasty and fewer subsequent cardiovascular events.<sup>1</sup> They carried out sensitivity analysis to measure the likely extent of this problem,<sup>4</sup> and they concluded that such unobserved confounders would have to meet strong conditions to affect their results.



**Could this reduce serious cardiovascular events?**

Ravi and colleagues also used landmark analysis, a technique designed to overcome a problem associated with comparative observational studies that have a "time to event" outcome. Commonly known as immortal time bias, this problem tends to exaggerate the benefits of a treatment (such as arthroplasty) because patients in a cohort are classified as untreated if they develop the outcome (a cardiovascular event) before they have the treatment.<sup>5</sup> This results in the untreated group tending to look worse.

Landmark analysis is a relatively straightforward technique that can be used to combat immortal time bias. It emerged in oncology research and has steadily gained popularity in other areas.<sup>6</sup> Before starting a study, researchers choose a landmark date or time point that will be considered as the start of follow-up. Ravi and colleagues chose a date three years after each patient's entry into the cohort. They first excluded all patients from their analyses who had a cardiovascular event (an outcome) before this date. They then classified as treated all patients who had an arthroplasty before the landmark date and classified as untreated all those who did not. Finally, they counted only

cardiovascular events (outcomes) that occurred after the landmark date. These elements combined help to eliminate immortal time bias, but, as with all statistical manipulations, landmark analysis has its limitations.

The technique classifies patients as untreated even if they are treated immediately after the landmark date. Furthermore, excluding patients who have a cardiovascular event before the date may cause loss of power. Choosing a date that is too early or too late has important consequences, and ideally selection should be clinically relevant.<sup>3</sup> When a different date is chosen, results and conclusions may change, which complicates the interpretation of results.<sup>7</sup> Ravi and colleagues ran their analyses again to check the sensitivity of their results to changes in the landmark date, and they found that the changes had no substantial impact on their findings.<sup>1</sup>

Landmark analysis is easy to execute and relatively easy to understand, so it is appealing to medical researchers. But we must remember that this method, as with other sophisticated techniques,<sup>8</sup> cannot completely eliminate confounding and bias in observational evaluations of treatments, even when combined with propensity score matching. Patients are still selected for treatment on the basis of many factors and it is rarely (if ever) possible to account for all of them. In that respect, the current study is persuasive but not conclusive.<sup>1</sup> The authors used the right techniques to minimise the well known limitations of observational analyses, but the techniques themselves have equally well established limitations. Comparative observational studies, such as this one,<sup>1</sup> should not be used to establish causality, and we should not, therefore, assume that joint replacement can definitely prevent serious cardiovascular events. Such studies can, however, lay a good foundation for future longitudinal research to explore causality.

**Competing interests:** I am funded through a studentship from the Multiple Sclerosis Society of Canada (2012/13-1213/14). I also had travel and accommodation costs for presenting at conferences covered by the endMS Research and Training Network (2011, 2012).

**Provenance and peer review:** Commissioned; not externally peer reviewed.

References are in the version on [bmj.com](http://bmj.com).

Cite this as: *BMJ* 2013;347:f6651

RESEARCH, p 14