QOF points: valuable to whom?

The UK's pay for performance system for primary care has produced some benefits, including reducing inequalities between practices, but **Stephen Gillam** and **Nicholas Steel** argue that it is time to reduce the proportion of general practitioners' income that it governs

ntroduced in 2004, the UK Quality and Outcomes Framework (QOF) is the most comprehensive national primary care pay for performance scheme in the world.¹ It includes financial incentives and information technology (computerised prompts and decision support) to achieve evidence based quality targets. The inducements are substantial, with a maximum of 1000 points available to practices, and an average payment per practice in 2011-12 of £130 (€150; \$205) for each point achieved.² Over half of these points are allocated to clinical indicators, which currently cover 22 chronic conditions, and the remainder to organisational indicators (see box, bmj.com).

The QOF was designed to improve the management of chronic disease by rewarding practices for delivering interventions linked to improved health outcomes for heart disease, diabetes, and other major scourges. The money to implement the scheme was intended to raise pay for general practices. Subsequently, proposed changes have been agreed by the General Practitioners Committee of the British Medical Association and the Department of Health. Negotiations over revisions to the General Medical Services contract in England having stalled, the Department of Health recently announced that it intends to impose changes to the QOF in 2013-14. These include:

- Raising the upper threshold for the percentage of patients receiving the relevant interventions in order to achieve maximum points, and therefore payment
- Discontinuing the organisational domain
- Implementing the National Institute for Health and Clinical Excellence (NICE) recommendations for new clinical indicators.<sup>3</sup> The effects of the QOF on quality of care have generated considerable debate. Do payments reflect better recording rather than better care, and do practices achieve high scores by "gaming" the system?<sup>4</sup> <sup>5</sup> Drawing firm conclusions about the effects of the QOF is difficult because it was implemented across the UK, leaving no comparator practices. Improved processes (such as treating hypertension) may not always translate into improved outcomes (such as stroke prevention)

because of other powerful influences on outcomes

such as differential access to care, non-modifiable risk factors (genetic), or patterns of comorbidity. Nevertheless, the debate is now being informed by an accumulating body of research into both the benefits and costs of the QOF. We consider the implications of the government's proposed changes, whether the QOF is likely to have improved the population's health, and how its effect could be augmented.

### How the QOF is constructed

Clinical areas are prioritised by an advisory committee at NICE and then undergo a formal consensus procedure followed by piloting in representative practices across England. The architects of this process have described the concept of "QOFability": reasons why certain issues can or cannot be made into QOF indicators. These include the prevalence of the clinical condition, the accuracy of data extraction from general practice clinical systems, the clarity of diagnosis, the relevance of incentivised actions, how directly change can be attributed to primary care staff, and consideration of any possible unintended consequences of introducing the proposed indicator.

The process is transparent, systematic, and robust—an impressive testimony to the experience and dedication of NICE and various associ-

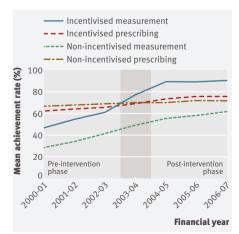


Fig 1 | Mean achievement rates of 148 general practices for quality of care indicators from 2000-01 to 2006-07. Performance indicators grouped by activity and whether they were incentivised under the QOF scheme, which came into force from 2004-05<sup>16</sup>

ated institutions. It has also been separated from the thorny process of contractual renegotiation. However, this elaborate filtering process inevitably prioritises straightforward technical and drug interventions. It mitigates against community based interventions that take primary healthcare teams beyond the surgery door to promote their practice populations' health.

Reliance on the randomised controlled trial or systematic review does not preclude indicators where the desired clinical action proves to be of questionable benefit. The incentive to reduce glycated haemoglobin concentrations below 7% in diabetic patients was revoked when subsequent research suggested this was associated with higher mortality than more liberal targets. The requirement to monitor people with depression using the patient health questionnaire PHQ-9 has also been reviewed with regard to the evidence for its benefit, and because it did not promote a holistic approach to assessing severity of depression.

An added complication is that clinical commissioning groups will shortly be working to the imperatives of the CCG Outcome Indicator Set. Commissioners could find themselves promoting activities in the interests of health gain (for example, to tackle obesity) that have been rejected as OOF indicators.

# Has the QOF improved population health?

The short answer is that we don't know. Bunker calculated that better healthcare had contributed about half of the 7.5 year increase in life expectancy observed over the second half of the 20th century. OQF does promote important preventive activities but, against a background of many interacting determinants, we are unlikely ever to be able to attribute declines in death rates to a multifaceted intervention like the QOF.

The nationwide implementation of the QOF means that there is no natural control population with which to compare population health. However, there may have been modest cost effective reductions in mortality and hospital admissions in some areas (such as epilepsy<sup>11</sup>), and modelling studies can shed some light on possible health gain. Fleetcroft et al modelled a potential saving of 11 lives per 100 000 people per year aggregated

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st effectiveness of Quality and Outcomes Framework indicators, 2004-05 <sup>13</sup>	
Incremental cost per QALY gained (£)	
989	
Dominant (less costly and more effective than comparator)	
58	
5623	
458	
Dominant	
15 654	
109	
2012	

across all clinical indicators and domains in the first year of the contract, with no further gain in the second year as performance for a typical practice already exceeded the target payment levels.<sup>12</sup>

Cost effectiveness can be modelled for only a minority of indicators (table). Walker et al concluded that some QOF incentive payments were cost effective, even with only modest improvements in care, although they took no account of the costs of administering the QOF scheme. They found average indicator payments ranged from £0.63 to £40.61 per patient, and the percentage of eligible patients treated ranged from 63% to 90%. <sup>13</sup> However, there is no relation between the size of payments in a clinical domain and the likely health gain resulting.

Inequalities in processes of care comparing the most and least deprived areas have narrowed. For example, Doran et al found that the gap in median achievement comparing practices from the most deprived and least deprived fifths narrowed from 4% to 0.8% between 2004 and 2007. 14

The QOF has helped consolidate evidence based methods for improving care by increasing the use of computers, decision support, provider prompts, and patient reminders and recalls. 15 It has resulted in better recorded care, enhanced processes, and improved intermediate outcomes for most conditions. The quality of care for chronic conditions has improved, but the extent to which these improvements track pre-existing trends is contested. 16 17 There is broad consensus that there has not been a dramatic effect. For example, measures for incentivised conditions such as cardiovascular disease, diabetes, and asthma improved over the first years of the framework at a faster rate than the pre-intervention trend and returned to previous rates of improvement in

subsequent years (fig 1).<sup>16</sup> The QOF seems to have reinforced smoking cessation activities in general practice. Achievement for conditions outside the framework was lower initially and has worsened in relative terms since (fig 2).<sup>5</sup>

Educational interventions and community development activities are not easily measured in the QOF. As a consequence 20% of indicators refer directly to drugs, and many others will require drug treatment in order for the targets to be met. The QOF therefore contributes to polypharmacy and rising treatment costs. Prescription rates for antidepressants, statins, and other drugs have risen. <sup>18</sup>

Doctors report improved data recording and team working, and nurses enhanced specialist skills. The same interview based studies suggest that the person centredness of consultations and continuity has been negatively affected. <sup>19</sup> <sup>20</sup> These sometimes conflicting findings, of course, reflect the way the QOF has been designed and developed.

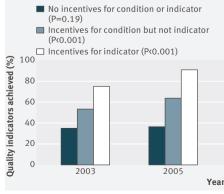


Fig 2 | Achievement for incentivised and unincentivised quality indicators in 2003 and 2005. Adapted from Steel et al<sup>5</sup>

### **Doctors' dilemmas**

Some of the QOF's design flaws are inherent to pay for performance schemes, 21 and little can be done about these. For example, there is growing acceptance that rewards can undermine motivation and worsen performance of complex cognitive tasks.<sup>22</sup> Economic research suggests that although financial incentives promote simple repetitive tasks, they can be counterproductive for tasks requiring more complex mental processes.<sup>23</sup> Financial incentives may encourage delivery of care that follows a simple algorithm, but algorithms are hard to apply meaningfully in the real world of individuals with a variety of symptoms, diagnoses, and expectations. This research implies that the complicated conceptual process of integrating suitable care for people with chronic conditions may not be enhanced by financial incentives.

These practical concerns chime with the ethical concerns of many clinicians that a reductionist approach to managing markers of chronic disease is incompatible with the humanitarian values of general practice. Health professionals need to place biomedical care in the context of their patients' concerns and life experience.<sup>24</sup> The algorithm approach to healthcare exemplified by the QOF is not the best way to achieve optimum disease management for individual patients. Even NICE guidelines may have limitations when applied to populations in primary care.<sup>25</sup> It may be possible to adapt guidelines to cater for people with multimorbidities-for example, through systematic cross referencing<sup>26</sup>—but they will always have shortcomings.27

So we are faced with conflicting conclusions about the QOF. It may have improved technical care for chronic conditions and has reduced inequalities in care. At the same time it may inhibit personalised care for the individual patient and complicate the management of multiple conditions over time. This does not diminish the ethical imperative to practise in the light of best evidence. The challenge is to deliver good quality technical care for medical conditions while simultaneously considering what is in the best interests of the whole person.

## Making progress

Much valuable experience has been accumulated since 2004 that can be used to inform decisions about how the QOF could be amended to maximise benefits and minimise harms. Changes to QOF are controversial because they represent a substantial proportion of general practitioners' incomes. Setting the political machinations to one side (the Department of Health has been clawing back from the original settlement since 2004), we believe that the incentive payments in the QOF comprise too large a proportion of general practice income. Money should be taken out of the

QOF and redirected to supporting general practice in other ways. There is no link between the size of the financial incentive and likely health gain from the activity incentivised, <sup>28</sup> and the improvements that the QOF has delivered could have been achieved with smaller incentives. The downsides of the QOF may remain with smaller incentives, but at least untied funding for general practices may help redress the imbalance it imposes.

What about thresholds? Given that average baseline performance has been above the level for maximum remuneration for all conditions since 2005, it is hard to argue against raising thresholds, as long as general practitioners can still exempt patients who may not benefit from the incentivised care. <sup>12</sup> <sup>29</sup>

The QOF's emphasis on single diseases does not best meet the needs of the two thirds of people over 65 who have multiple conditions. QOF targets will no doubt continue to be used for simple comorbidity, but the complex nature of managing multiple comorbidities means that payment for performance is only part of their solution.

Few indicators deal with major determinants of health such as obesity or physical activity. It has been proposed that a fixed proportion of QOF payments be dedicated to public health activities. How this would work is unclear. It would be hard to justify loosening the standards of admissible evidence—and even harder to sell to practitioners already wary of being used as tools for social engineering. However, greater discretion to set local public health related targets—for example, to support local obesity management programmes or promote exercise—could be one solution.

Our principal concern has been with clinical indicators; the effect of organisational indicators has not been evaluated. However, the indirect effects of good medicines management, enhanced education, and training on health outcomes may nevertheless be substantial. We cannot assume that performance will be sustained if these indicators are abolished. Imaginative incentives—for example, for staff training in motivational interviewing and behaviour change techniques—might promote population health. Shared decision making can take account of patient preferences and reduce healthcare costs. <sup>30</sup> Decision aids have the potential to be incorporated in the QOF.

Finally, there is a strong argument for differential pricing that rewards practices serving more deprived populations in areas where practice population turnover is high and medical recruitment is difficult.<sup>31</sup>

### **Conclusion**

The variation in pay for performance schemes between countries reflects different historical and organisational contexts. The burgeoning research literature shows us that benefits to patient care are

# The algorithm approach to healthcare exemplified by the QOF is not the best way to achieve optimum disease management for individual patients

at best modest, and, with so much uncertainty regarding the effects of performance related pay, policy makers are well advised to reduce the proportion of general practice income commanded by QOF. 6 32-34 The continued evolution of indicators and payment thresholds is likely to become integrated with other quality improvement activities in general practice and with commissioning activity. Future incentives for general practices might include balanced sanctions for poorly performing practices, as there is some evidence to support the use of penalties alongside rewards. 35 The evolution of the QOF, given its scale and sophistication, will attract continuing scrutiny from policy makers across the globe.

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We thank Bob Fleetcroft for his comments.

Competing interests: SG is a GP principal and both authors are members (unpaid) of the QOF advisory committee for NICE. The views expressed are not those of the NICE advisory committee.

**Provenance and peer review**: Not commissioned; externally peer reviewed.

- 1 NHS Employers and the General Practitioners Committee. Quality and outcomes framework for 2012/13. Guidance for PCOs and practices. 2012. www.nhsemployers.org/ Aboutus/Publications/Documents/ODF 2012-13.pdf.
- 2 Campbell S, Lester H. Pay-for-performance schemes in primary care: what have we learnt? In: Gillam S, Siriwardena AN, eds. The quality and outcomes framework: QOF transforming general practice. Radcliffe Publishing, 2011:137-46.
- 3 Hakin B. DH letter to PCT chief executives. 2012. www.dh.gov. uk (Gateway ref 18276).
- 4 Doran T, Fullwood C, Gravelle H, Reeves D, Kontopantelis E, Hiroeh U, et al. Pay-for-performance programs in family practices in the United Kingdom. N Engl J Med 2006;355:375-84.
- 5 Steel N, Maisey S, Clark A, Fleetcroft R, Howe A. Quality of clinical primary care and targeted incentive payments: an observational study. Br J Gen Pract 2007;57:449-54.
- 6 Gillam S, Siriwardena N, Steel N. Pay-for-performance in the UK: the impact of the quality and outcomes framework systematic review. Ann Fam Med 2012:10:461-8.
- 7 Sutcliffe D, Lester H, Hutton J, Stokes T. NICE and the quality and outcomes framework (QOF) 2009-11. Qual Prim Care 2012;20:47-55.
- 8 Gerstein H, Miller M, Genuth S, ACCORD Study Group. Longterm effects of intensive glucose lowering on cardiovascular outcomes. N Engl J Med 2011;364:831-41.
- 9 Primary Care Quality and Outcomes Framework Indicator Advisory Committee. Confirmed minutes of the committee's meeting held on 8th June 2011. www.nice.org.uk/media/E19/EA/ NICEIndependentPrimaryCareQOFAdvisoryCommittee 080611ConfirmedMinutes.pdf.
- 10 Bunker J. The role of medical care in contributing to health improvement within society. *Int J Epidemiol* 2001;30:1260-3.
- 11 Shohet C, Yelloly J, Bingham P, Lyratzopoulos G. The association between the quality of epilepsy management in primary care, general practice population deprivation status and epilepsy-related emergency hospitalisations. Seizure 2007;16:351-5.

- 12 Fleetcroft R, Parekh-Bhurke S, Howe A, Cookson R, Swift L, Steel N. The UK pay-for-performance programme in primary care: estimation of population mortality reduction. *Br J Gen Part* 2010-60-8345-52
- 13 Walker S, Mason AR, Claxton K, Cookson R, Fenwick E, Fleetcroft R. Value for money and the quality and outcomes framework in primary care in the UK NHS. *Br J Gen Pract* 2010;60:213-20.
- 14 Doran T, Fullwood C, Kontopantelis E, Reeves D. Effect of financial incentives on inequalities in the delivery of primary clinical care in England: analysis of clinical activity indicators for the quality and outcomes framework. *Lancet* 2008;372:728-36.
- 15 Gillam S, Siriwardena AN. The quality and outcomes framework: triumph of evidence or tragedy for personal care? In: Gillam S, Siriwardena AN, eds. The quality and outcomes framework: QOF transforming general practice. Radcliffe Publishing, 2011:156-66.
- 16 Doran T, Kontopantelis E, Valderas JM, Campbell S, Roland M, Salisbury C, et al. Effect of financial incentives on incentivised and non-incentivised clinical activities: longitudinal analysis of data from the UK Quality and Outcomes Framework. BMJ 2011;342: d3590.
- 17 Hippisley-Cox J, Vinogradova Y, Coupland C. Time series analysis for 2001-2006 for selected clinical indicators from the quality and outcomes framework: final report for the information centre for health and social care. Information Centre for Health and Social Care, 2007.
- 18 MacBride-Stewart SP, Elton R, Walley T. Do quality incentives change prescribing patterns in primary care? An observational study in Scotland. Fam Pract 2008;25:27-32.
- 19 Maisey S, Steel N, Marsh R, Gillam S, Fleetcroft R, Howe A. Effects of payment for performance in primary care: qualitative interview study. *J Health Serv Res Policy* 2008;13:133-9.
- 20 Campbell SM, McDonald R, Lester H. The experience of pay for performance in English family practice: a qualitative study. Ann Fam Med 2008;6:228-34.
- 21 Woolhandler S, Ariely D, Himmelstein D. Why pay for performance may be incompatible with quality improvement. BMJ 2012;345:e5015.
- 22 Glasziou P, Buchan H, Del Mar C, Doust J, Harris M, Knight R, et al. When financial incentives do more good than harm: a checklist. *BMJ* 2012;345:e5047.
- 23 Ariely D, Gneezy U, Loewenstein G, Mazar N. Large stakes and big mistakes. *Rev Econ Stud* 2009;76:451-69.
- 24 Heath I. Divided we fail. The Harveian oration 2011. www. rcplondon.ac.uk/sites/default/files/harveian-oration-2011web-navigable.pdf.
- 25 Scullard P, Abdelhamid A, Steel N, Qureshi N. Does the evidence referenced in NICE guidelines reflect a primary care population? Br J Gen Pract 2011;61:e112-7.
- 26 Guthrie B, Payne K, Anderson P, McMurdo M, Mercer S. Adapting clinical guidelines to take account of multimorbidity. BMJ 2012;3345:e6341.
- 27 Barnett K, Mercer S, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet* 2012;380:37-43.
- 28 Fleetcroft R, Steel N, Cookson R, Walker S, Howe A. Incentive payments are not related to expected health gain in the pay for performance scheme for UK primary care: cross-sectional analysis. BMC Health Serv Res 2012;12:94.
- 29 Fleetcroft R, Steel N, Cookson R, Howe A. Mind the gap! Evaluation of the performance gap attributable to exception reporting and target thresholds in the new GMS contract: national database analysis. BMC Health Serv Res 2008;8:131.
- 30 Mulley A, Trimble C, Elwyn G. Stop the silent misdiagnosis patients' preferences matter. BMJ 2012;345:e6572.
- 31 Stewart WM, Bruce G, John F, Graham CMW, Julian TH. Multimorbidity and the inverse care law in primary care. BMJ 2012;344:e4152.
- 32 Christianson JB, Leatherman S, Sutherland K. Financial incentives, healthcare providers and quality improvements. A review of the evidence. Health Foundation, 2007.
- 33 Greene SE, Nash DB. Pay for performance: an overview of the literature. *Am J Med Qual* 2009:24:140-63.
- 34 Scott A, Sivey P, Ait Ouakrim D, Willenberg L, Naccarella L, Furler J, et al. The effect of financial incentives on the quality of health care provided by primary care physicians. Cochrane Database Syst Rev 2011;9:CD008451.
- 35 Dixon-Woods M, McNicol S, Martin G. Ten challenges in improving quality in healthcare: lessons from the Health Foundation's programme evaluations and relevant literature. BMJ Qual Safety 2012;21:876-84.

Cite this as: BMJ 2013;346:f659

# How the e-patient community helped save my life

**Dave deBronkart**—otherwise known as e-Patient Dave—describes his four year odyssey from cancer diagnosis to international patient superstar. His journey shows the contribution that patients can make to the complexities of medicine

n April 2009 I found myself on the front page of the *Boston Globe*. A mere cancer patient, I'd written a blog post about my medical record. The *Globe*'s reaction—on page 1—was my first glimpse of a big question: how can a patient say anything about medicine that's worthy of attention?

It was the start of an improbable odyssey, leading to speaking engagements at 200 meetings, a Salzburg global seminar on shared decision making, co-chairmanship of the Society for Participatory Medicine, testimony on government policy, events in many countries, and a TEDx talk<sup>3</sup> that is in the top half of most viewed ever and has subtitles in 26 languages. Time and again I find myself wondering what people have heard that draws such interest; I wouldn't have been so bold as to predict it.

I think it is because, although I understand science—I love it, and I'm alive because of it—I also sense a substantial disconnect between what patients value and what medicine offers. And this raises the question: we all agree medicine should provide value for money, but who gets to say what value is?

### I'm not anti-doctor

I was saved by brilliant science and top notch clinicians. Diagnosed incidentally with stage IV, grade 4 metastatic renal cell carcinoma, I had bone metastases in my femur (which eventually fractured), ulna, and cranium; five metastases in my lungs; and muscle metastases in my thigh and tongue. Yet six months after diagnosis my treatment ended: I've not had a drop of anything since. A superb surgeon removed my kidney and adrenal gland; another repaired my femur (twice), and a skilled oncology team tended me through a difficult and dangerous treatment. Today I am well.

My gratitude goes out to every person who worked on development of the drug and the new protocol I received. Thank you to science, and to every clinician whose training and experience led them to be in the world class team at Beth Israel Deaconess Medical Center that saved my life. My family add their thanks.

### What is value and who provides it?

What does my experience tell us about value? To understand a changing industry we must be clear about the elements that constitute value in medicine. Clearly, my team's achievements are valuable. Let's list some:

Awareness of status—I had no idea I was sick; I'd been tired and slowly losing weight, but at age 56 neither seemed a problem. I was unaware of my cancer until doctors spotted a shadow in my lung during a routine shoulder x ray examination.

Accurate diagnosis—Radiology quickly suggested

renal cell carcinoma, but my doctors didn't leap to a plan until a biopsy made it certain.

Current information on treatment options—I've since learnt that three out of four patients with metastatic renal cell cancer never hear of the treatment I got. high dosage interleukin-2 (IL-2). At the time it was the only drug that sometimes produced this result. Surgical excellence—I was so sick that my nephrectomy had to be laparoscopic, which offers quicker recovery so the IL-2 could start. My surgeon says he almost had to fall back to open surgery. His skill was valuable. As was that of the orthopaedic surgeon: my leg works. I am repaired. Clinical excellence— My unit treats 100 cases a year, which has given staff valuable practical knowledge. In the 1990s clinical trial used to approve IL-2. 4% of patients died from side effects. Today at my hospital only two of the last 600 patients have died. Furthermore, the response rate today is nearly double what it was in the 1990s; my oncologist, David McDermott, says the principal difference is that we've improved our ability to select likely responders.

I could go on, but the pattern is clear: there are many types of clinical value in the modern medical centre. Yet the institution isn't the only source of value. These system factors are valuable, too.

Access to the service—In my American case it was insurance coverage; while uninsured I'd postponed the appointment. But in any case if there's no access to a service, potential value goes unharvested. (Economically, the system is inefficient.)

Access to top notch information—In my case, this was first through access to a top medical centre, but as we'll see in a moment, that's not the only path. Choice of provider—I chose to be treated at a great medical centre, even though it's an hour from home. To get there I have to drive past a dozen closer hospitals; only one offers IL-2 (and it has far fewer cases). Being allowed to get care there was clearly valuable to me, and it let my providers exercise the competence they'd developed.

# My being engaged and informed created value, too Consider the following, which are neither provider skills nor system issues, yet are clearly valuable.

Taking action to get checked—My cancer was discovered because I got a check-up, on general principle.

Planning ahead—Knowing that my leg might fracture, I asked what we should do if it happened. This led to a plan that worked: the fracture happened at 5 30 am, and I was in hospital by 10 am, in a methodical, non-dramatic fashion.

Being informed about choosing providers—Years earlier a relative, an intensive care nurse, had shared her sadness that some patients arrive at her tertiary centre too late to save. That's what led me to connect to an academic centre long before my crisis. In a real sense, she saved my life by giving me that information, and I saved my life by acting on it.



And then consider these other factors that are outside the medical establishment. My online patient community has better information than most hospitals. ACOR.org is a network of simple plain-text listservs for patients with various cancers. One of its best is for renal cell carcinoma, and as soon as my diagnosis was confirmed, my primary physician (Danny Sands) said, "You're an online kind of guy, Dave—you might like to join this

group." Within two hours of posting my first message, I got facts and practical advice that to this day don't exist in any journal article or establishment website.

As a responsible engaged

patient, I constantly check with my clinicians. Dr McDermott has verified that the information is accurate. If peer review is the only true path to reliability, how could a patient community have better facts?

Some medical websites I consulted said 7% of IL-2 patients respond; the clinical trial, published in the National Comprehensive Cancer Database, said 14% respond and 4% die. ACOR told me response had risen to 15%; my hospital said it was up to 20%, with only rare deaths. That's a massive difference compared with the official "facts." How can this be?

I reported the 20% response rate to ACOR. The community's knowledge was immediately updated. It reminds me of the 2006 war between Encyclopaedia Britannica and Wikipedia. Both were found to have similar error rates<sup>5</sup>—but Wikipedia's were fixed within days.

### ACOR's practical information may have saved my life

As a responsible engaged patient, knowing that IL-2's side effects might kill me, I sought to prepare myself. First I sought authoritative sources; there I found dry facts: "Side effects are often severe and rarely fatal, and include..." I thought, "What am I supposed to do with that?" and turned to my peers on ACOR. I asked, "You who've done this—what was it like? What do I need to know?" From them I received 17 firsthand stories—a wide range of experiences. I felt prepared—and today Dr McDermott says, "You were really sick. I don't know if you could have tolerated enough medicine if you hadn't been so well prepared." In this case valuable—as in potentially lifesaving—information came from outside the establishment.

### A new view of value

To understand these anecdotes we need to understand what value is. That question is at the core of what Christensen dubbed disruptive innovation<sup>6</sup>; more recently, and more aptly, cardiologist Eric Topol has described it as "creative destruction," in which previously bundled elements of value

become unbundled, making new things possible. If you're blind to this, it hurts when it hits.

It happened to me in the 1980s, when my industry fell apart. I worked in typesetting, and along came the Mac. "Hello," said the first ads. Its first seminal application was desktop publishing, which enabled the great unwashed to use fonts, one of the core assets in the typesetting bundle. Another was the ability to lay out pages, which

I turned to my peers on ACOR

and asked, "You who've done

this—what was it like?

What do I need to know?"

had previously required cut and paste or immensely expensive systems. Another was software to count character widths and hyphenate words at the end of a line—not to mention more

complex tasks, such as composing complex tables to display data more clearly. Last was the Laser-Writer's ability to print complete pages. Everything about desktop publishing was far lower quality than what we in the trade offered, but the people with the need—the ultimate stakeholders—could decide for themselves what was important to them. What they valued.

Today all those publishing capabilities exist, to varying degrees, in Microsoft Word and your home printer. And you probably have fonts in your phone. We who believed our expertise was the only source of value got a rude awakening.

I'd never say that medicine is like typesetting, but there are parallels that help us understand change as industries digitise. And, in particular, truths that can help us answer "What's going on here?" in the stories above.

To understand what's happening in medicine and more accurately see the future, we need to articulate what those particles of value are—so we can anticipate their "creative destruction," so we can avoid being blind to genuine value when it arises outside our model of thinking, so we can be effective in designing new solutions.

### "Doc Tom" saw it coming

As I noted two years ago on the *BMJ* blog, <sup>8</sup> I'm a disciple of Dr Tom Ferguson, a leader of patients as informed, engaged partners. He was a visionary when he wrote these words 10 years ago: "The emerging world of the e-patient cannot be fully understood and appreciated in the context of preinternet medical constructs."

In another article he commented, "Online patient-helpers with a chronic disease can be valuable resources for other patients with the same condition . . . Clinicians must keep up to date on a wide variety of medical conditions while seeing dozens of patients a day. Patient-helpers . . . will typically know only about their one disease, but since they can devote a great deal of time to it, their knowledge within that single narrow niche can be impressive." <sup>10</sup>

Writing with Gilles Frydman, founder of ACOR, Ferguson predicted that "the 21st century will be the age of the net empowered medical end user and that the patient driven online support networks of today will evolve into more robust and capable medical guidance systems that will allow end users to direct and control an ever growing portion of their own medical care. Doctors who continue to believe that their patients are inherently incapable of navigating the plentiful health resources of the internet will find their net savvy patients leaving them for other doctors. By contrast, those wise and caring doctors who realise that we may have just as much to learn from our patients as they have from us should do very well indeed."9

Ferguson saw the future of internet enabled patient connections. At a deeper level, though, he saw the value patients were finding, creating, and even defining, on their own.

The baby boomer surge is forcing society to face decisions about costs—and particularly what is valuable. It's senseless for clinicians and governments to bear these choices alone; a sad effect of needless paternalism is that it places a false burden on responsible people. In other industries value is defined by the ultimate stakeholder—the one who benefits, or not, from the service. We should do the same in medicine.

We hear that if given the chance, patients will spend the earth—but the evidence says otherwise. 11

### Saved by value, from clinicians and peers

I close by reinforcing how grateful I am for excellence in medicine—and for the additional value I received from peers. Two years after my treatment I had the deeply moving experience of walking my daughter Lindsey down the aisle at her wedding. And last Christmas she gave me a jigsaw puzzle, whose first solved portion said, "I can't wait to meet you!" It was an ultrasound: I have lived to see the birth of my first grandchild, this July. If that's not value, I don't know what is.

The value delivered by skilled clinicians is still there, but now we can see that it's no longer the only source—and sometimes it's not even the best. According to patients. And even according to my oncologist.

Please, let patients help improve healthcare. Let patients help steer our decisions, strategic and practical. Let patients help define what value in medicine is.

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Competing interests: None declared.

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

References are in the version on bmj.com.

Cite this as: BMJ 2013;346:f1990