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## Improving vascular health: are pills the answer?

### Lowering the statin treatment threshold raises important questions

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Guidelines from the National Institute for Health and Clinical Excellence,<sup>1</sup> the United States,<sup>2</sup> and Europe<sup>3</sup> recommend statins for people with cardiovascular disease and for those at high risk of developing disease on the basis of an individual risk assessment. Although there has been much debate about the optimal risk assessment tool, surprisingly, the risk threshold above which statins are recommended has been less hotly debated. A risk of developing cardiovascular disease of greater than 20% over 10 years—or greater than 10% over five years—is widely used as the cut-off point for prescribing statins. The results of a recent meta-analysis of data from the Cholesterol Treatment Trialists Collaborators directly challenges the consensus over this threshold.<sup>4</sup>

Statin reduce the relative risk of major vascular events by around 20% per 1 mmol/L reduction in low density lipoprotein-cholesterol—the typical effect on lipids produced by a low to moderate dose of statin. The striking finding from the new meta-analysis is that the established beneficial effects were seen across a broad spectrum of vascular risk, including people with a five year risk of vascular disease of less than 5%, well below the current threshold for statin treatment. Therefore, people at low to medium risk of disease, who are seldom currently prescribed a statin, may be missing out on a treatment that has been proved to reduce the incidence of future vascular events. Should clinical guidelines now be changed and statins recommended for a larger proportion of the population?

We suggest four factors that warrant detailed consideration before such a revolutionary change in guidance is made. Firstly, cost is a consideration. When initially shown to be effective, statins had 10 year patents and were expensive. Even though relative measures of benefit (such as the rate ratio) are similar across different groups, absolute measures of benefit (such as numbers of events prevented) vary by baseline risk. It is cheaper to prevent one heart attack by treating 100 people at very high risk of vascular



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- [bmj.com poll](#): Should all adults over 50 get statins? Votes: Yes: 189 (21%); No 704 (79%)
- [Research](#): Unintended effects of statins in men and women in England and Wales (*BMJ* 2010;340:c2197)
- [Research](#): Use of blood pressure lowering drugs in the prevention of cardiovascular disease (*BMJ* 2009;338:b1665)
- [bmj.com/blogs](#): Richard Smith: Statin arguments <http://blogs.bmj.com/bmj/2011/01/25/richard-smith-statin-arguments/>

disease than by treating 1000 people at low risk. However, as patents expire, cheap generic versions of statins have become available, including most recently atorvastatin.<sup>5</sup> Although it may be relatively cheap to widen the use of statins use now, a rigorous cost effectiveness analysis of this approach is yet to be completed.

Secondly, statins cause harms. Myopathy, and the more serious rhabdomyolysis, are important, if uncommon, adverse effects (0.1/1000 people treated for a year or less).<sup>6,7</sup> Statins increase the risk of haemorrhagic stroke,<sup>4</sup> although the numbers of ischaemic strokes prevented outweighs the increased risk of haemorrhagic stroke. There has been great concern that statins may increase the risk of diabetes.<sup>8</sup> A small increased risk seems likely,

but again, the known benefits of statins on vascular outcomes probably outweigh this risk in all groups studied so far. Previous concerns that statins may increase the risk of cancer have been contradicted by evidence from large scale observational studies and trials.<sup>7,9</sup> However, the potential for increased rates of harm with increased statin use cannot be ignored, and ongoing vigilance for adverse effects is needed.

**There is a danger that the quest for a healthier world is replaced by a quest to get more and more people taking tablets**

A third important factor relevant to any discussion of widening the use of statins is the viewpoint of the patient, and unanswered questions abound. For patients to decide whether or not to take statins more information is needed on outcomes that are relevant to patients. A patient may ask, “Will statins extend my life?” This intuitive measure of impact is rarely reported and may give surprising results. For example, even among high risk patients undergoing coronary artery bypass grafting compared with medical therapy, surgery extended survival at 10 years by only about 35 weeks.<sup>10</sup> Extending life by a moderate amount may be important for some patients but not for others. Do patients want to delay vascular events? The answer is probably “yes.” However, death is inevitable and when it comes some people may prefer a sudden fatal vascular event to a more drawn out alternative. Do patients on lifelong statin treatment have better quality of life? We don't know for sure.

Lastly, why take pills to treat the ills of society? Vascular events occur largely because of the consequences of industrialised living associated with poor diet, low levels of exercise, and smoking. These are (potentially) modifiable factors. Sustainable improvements in human health—not restricted to vascular disease and accessible to rich and poor alike—could be achieved by improving diets, encouraging physical activity, and reducing smoking. The alternative scenario—of whole populations taking a daily tablet to mitigate against unhealthy lifestyles—is far from attractive. Even the consideration of this option may suggest that the medical profession is losing its way in efforts to allow people to live healthier longer lives. If we developed a tablet that prevented the adverse effects of smoking, would we advocate widespread consumption, forgetting that a better aim would be to stop people smoking in the first place?

Evidence that a drug treatment reduces the relative risk for vascular events is noteworthy but not sufficient to warrant revising current treatment thresholds. There is a danger that the quest for a healthier world is replaced by a quest to get more and more people taking tablets.

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## Exercise may need to be performed at moderate-hard intensity for it to have a meaningful effect on depression

# Exercise to treat depression

Does not seem to benefit patients in clinical settings who receive good standard care

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There has been considerable research interest in the effects of exercise on depression over the past three decades and many systematic reviews have reported moderate to large effect sizes, with the standardised mean difference for the most recent Cochrane review being  $-0.82$  (95% confidence interval  $-1.12$  to  $-0.51$ ).<sup>1-3</sup> A new linked trial (TREATment of Depression with physical activity (TREAD)); doi:10.1136/bmj.e2758 adds to this evidence base.<sup>4</sup>

At first glance reviews suggest that exercise is effective in the treatment of depression. However, most trials included in systematic reviews recruited small numbers of patients, had a short follow-up, and did not adequately conceal randomisation or recruited non-clinical community volunteers (or both). Volunteers are more likely to be motivated to exercise and may be less severely depressed than people identified in clinical settings. Subgroup analyses that included only the higher quality trials in the Cochrane review reduced the effect size to  $-0.42$  ( $-0.88$  to  $0.03$ ),<sup>1</sup> casting doubt on the main finding.

In 2009 the UK National Institute for Health and Clinical Excellence recommended that people with persistent subthreshold depressive symptoms or mild-moderate depression should be advised of the benefits of exercise,<sup>5</sup> despite a lack of high quality evidence to support such a recommendation. The investigators in the current trial tried to remedy the methodological concerns of previous trials and answer definitively whether or not physical activity is an effective treatment in patients diagnosed with depression.<sup>4</sup>

TREAD was a large ( $n=361$ ) methodologically rigorous trial that enrolled participants from primary care who presented with depression that had been confirmed by standardised clinical interview. The intervention was theory based and patient centred, and it aimed to be deliverable within the health service by physical activity facilitators, without unsustainable



COLIN HAWKINS/SPL

### NICE recommends advising depressed patients to exercise

resource implications. TREAD compared usual care plus physical activity with usual care only and reported no significant difference in levels of depression between the groups at follow-up over one year.

These negative findings contrast with more positive findings from systematic reviews but are perhaps not surprising, particularly when considered alongside the results of a more recent meta-analysis of 13 trials that had recruited only patients with clinically diagnosed depression.<sup>6</sup> This meta-analysis reported that physical exercise showed a small effect on depression (standardised mean difference  $-0.40$ ,  $-0.66$  to  $-0.14$ ). However, no significant difference was found when the analysis was restricted to trials with follow-up beyond the end of the intervention ( $-0.01$ ,  $-0.28$  to  $0.26$ ) or to the three high quality trials ( $-0.19$ ,  $-0.70$  to  $0.31$ ), which suggests that exercise may not be effective in this population in the long term. Should we therefore conclude, on the basis of recent evidence, that physical activity has no effect on depression in clinical populations?<sup>4 6</sup>

Not necessarily. In the TREAD trial, usual care could comprise antidepressants, counselling, referral to exercise on prescription schemes, or referral to secondary care mental health services. Patients in both groups therefore already received high quality care, and 57% were taking antidepressants at recruitment. It may have been difficult for the addition of a physical activity intervention to make an appreciable difference. In addition, about 25% of participants were already meeting the current UK government guidelines for physical activity at baseline (the target level for the intervention),<sup>7</sup> and they could feasibly have

already been gaining any benefits that physical activity might provide, leaving little room for the intervention to make a difference.

Adherence was good, and 70% of participants received an adequate dose of the intervention, which is an achievement considering that it is difficult to motivate people who are depressed to commit to an exercise intervention.<sup>8</sup> However, although a significant difference in physical activity between groups was reported at follow-up, this was relatively small and based on self reported data, which are prone to overestimation. The relatively severe depression of the recruited population (mean Beck depression inventory score 32 points) may have affected the levels of physical activity achieved. Limited information was available on the intensity of physical activity achieved, and this might be important because exercise may need to be performed at moderate-hard intensity for it to have a meaningful effect on depression.

To date there has been insufficient research on how the intensity and overall duration of exercise affects depression; future trials should include an objective measurement of physical activity. Any future trials should also, as in the TREAD trial, measure longer term outcomes and use standardised clinical interviews to diagnose depression to ensure the usefulness of the findings in a population with clinically diagnosed depression.

What should doctors advise their patients who present with depression? Within a clinical setting, for patients who are well managed on usual drugs or psychological treatments (or both), advice and support to be physically active does not seem to offer additional benefit and should not be given as standard. Indeed, recommending exercise to very depressed patients may worsen any thoughts of "failure" if they are unable to comply with the recommendation. However, positive results from trials in volunteers suggest that patients who are motivated to exercise and seek support to do so might benefit and should be supported in achieving this behavioural change.

Competing interests: Both authors are currently working with two of the TREAD authors (DJ Sharp, KM Turner) on a trial in a different patient population.

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## Strategies to optimise clinical outcomes for patients with diabetes

Good professional consultation skills and self management education work, but effects don't endure

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It is well recognised that people with diabetes, both young ones with type 1 disease and adults with type 2 diabetes, need to develop skills in self management to manage their condition successfully. In the past few decades different strategies aimed at promoting self management have been developed and tested across a wide range of patient groups and settings. Two linked papers, which examine two different approaches delivered in routine practice, improve our understanding of the longitudinal dose-response relation between educational and consultation interventions and improvements in the self management behaviours and subsequent health outcomes of patients with diabetes.<sup>1 2</sup>

A systematic review found that group based programmes for self management strategies in type 2 diabetes were effective in terms of improving blood glucose, blood pressure, body weight, and requirement for antidiabetes drugs.<sup>3</sup> The Diabetes Education and Self Management for Ongoing and Newly Diagnosed (DESMOND) programme was developed in the United Kingdom and tested in 824 patients who had been newly diagnosed with type 2 diabetes in a clustered randomised trial in primary care. At one year follow-up, the programme was shown to be effective with regard to weight loss, smoking cessation, and depressive symptoms but not glycaemic control.<sup>4</sup> On the basis of these findings, the six hour structured DESMOND education programme was deemed to be cost effective.<sup>5</sup> In the first of the linked studies, the DESMOND group reports on a uniquely long trial follow-up of three years.<sup>1</sup> The authors were able to collect biomedical data from 83% of the original sample and psychosocial data by postal questionnaires from 70% of the participants. Participants who were lost to follow-up were younger, less healthy, and more depressed than those who were followed up. Over time, a non-

significant small increase in glycated haemoglobin (HbA<sub>1c</sub>) was seen in both the usual care and the DESMOND group, with a mean HbA<sub>1c</sub> of 64 mmol/mol (8.0%), and no differences were found in other biomedical or lifestyle outcomes or use of drugs. The benefits in terms of non-smoking and weight loss seen at 12 months were not sustained.

From the data presented it is not clear at what point in time the improvements were lost. Interestingly, significant differences in illness beliefs, as measured by the illness perception questionnaire, were sustained, suggesting a more correct "mental model" of diabetes in people exposed to DESMOND. For example, DESMOND participants were more likely to agree on the chronic nature of diabetes and their personal responsibility in managing their symptoms. Social cognitive theories of behavioural change postulate that changes in a person's illness beliefs or representations drive the adoption of health behaviour changes, with subsequent changes in medical outcomes. However, various illness beliefs do not have equal relevance for maintaining acquired behaviour changes at a later stage.<sup>6</sup> Khunti and colleagues rightly point to



Self management requires education and motivation

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the need for additional ongoing education and support in primary diabetes care to help sustain the initial benefits of the self management programme. For patients with poorly controlled diabetes, relatively short and targeted behavioural interventions are available and were shown to be effective.<sup>7</sup>

It is difficult to achieve strict glycaemic control in young people with type 1 diabetes, particularly during adolescence. Large differences are seen between centres,<sup>8</sup> however, that are probably explained largely by differences in target setting by diabetes teams.<sup>9</sup> Thus, providing help for healthcare teams to improve their ability to express and discuss goals for treatment could indirectly improve treatment outcomes for young people with type 1 diabetes. In the second linked study, Robling and colleagues present

the 12 month results of a large well designed cluster-randomised trial conducted in 26 paediatric diabetes clinics in the UK where healthcare teams were offered the Talking Diabetes learning programme, which is informed by motivational interviewing and aimed at improving healthcare professionals' consulting skills.<sup>2</sup> Shared agenda setting, which ensures that concerns of patients and professionals are dealt with, is central to this approach. In Robling and colleagues' trial, 79 professionals were trained, and 359 children with type 1 diabetes (mean age 10.6 years) and their care givers were included. No differences were found in HbA<sub>1c</sub> or quality of life at 12 months, which is disappointing, although trained teams were more skilful than controls in guiding, agenda setting, and consultation strategies, even though absolute levels of skilfulness were low. By contrast, a previous multicentre randomised controlled trial of motivational interviewing showed significant improvements in glycaemic control and psychosocial outcomes in adolescents with type 1 diabetes.<sup>10</sup> In that study, the intervention was delivered outside the clinic by a skilled nurse specialist and with more frequent opportunities for contact. The difference in outcomes between the two trials might be explained by differences in the intensity and the quality of the intervention delivered.

That both the DESMOND and the Talking Diabetes trial were carried out in routine practice adds to the external validity of their findings. It is important to understand the association between the skills of practitioners, patients' self management behaviours, and subsequent health outcomes for patients with diabetes, but we must not lose sight of the importance of glycaemic control. By international comparison the generally poor glycaemic control found in the Talking Diabetes study is worrying (mean HbA<sub>1c</sub> of 75 mmol/mol).<sup>8 11</sup> Perhaps we should focus again on the setting of appropriate targets by professionals who care for patients with diabetes and the patients themselves. Is it time to raise the bar?

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- ▶ Research: Evaluation of a peer led parenting intervention for disruptive behaviour problems in children: community based randomised controlled trial (*BMJ* 2012;344:e1107)
- ▶ Editorial: Riots on the streets (*BMJ* 2011;343:d5248)

## The British government's Troubled Families Programme

A flawed response to riots and youth offending

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The British government has recently established the Troubled Families Programme in response to the riots in England in 2011, scaling up a non-negotiable version of the previous government's Family Intervention Projects. Their aim is to prevent further riots. Key workers will assess the needs of families identified as being troubled and coordinate a year long programme of intensive family support to tackle antisocial behaviour, misuse of drugs and alcohol, and youth crime. However, evidence for the effectiveness of family intervention projects is weak, being made up of small scale evaluations without randomised comparison groups.<sup>1</sup> A systematic review commissioned by the previous government found no studies to support the claim that such interventions improve outcomes for families.<sup>2</sup>

Even if the programme were effective for those receiving it, targeting 120 000 families, which represent less than 2% of all families in England, would miss most future rioters and young offenders. Public health scientists know that disease prevention approaches aimed only at people identified as at high risk of most non-communicable diseases are unlikely to have much effect at the population level when risk follows a bell shaped curve, because in such cases most disease arises from those at low to medium risk. This seems also to be true for youth offenders. In London, the "worst" 5% of families account for only around a quarter of all offenders, with a similar pattern emerging in other countries, such as the United States.<sup>3</sup>

The programme may also inadvertently cause harms. Targeted interventions can sometimes cause harm because labelling individuals can exacerbate risky behaviours. The compulsory



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**Intensive family support aims to root out problematic behaviour**

nature of the programme could make it particularly liable to bring about such harms. Some activities within the programme will bring together troubled families and young people, and some studies have suggested this can also amplify risky behaviour.<sup>4</sup>

A historical example of a somewhat similar intervention illustrates the potential for well intended targeted interventions to cause harm. The Cambridge-Somerville project targeted pre-adolescent boys in low income neighbourhoods in Massachusetts in the 1940s.<sup>4 5</sup> The intervention involved regular home visits by support workers to mentor youth, deal with family needs, and coordinate services, and boys in the intervention were encouraged to participate in community groups, sports, and summer camps. When followed up 30 years later, those who had received the intervention had higher rates of mortality, alcohol dependence, serious mental illness, and criminal convictions than those in the comparison group. Moreover, adverse effects seemed to result from intervention components that aggregated at risk boys into group activities. Caution is clearly needed when applying evidence from an intervention that, although somewhat similar, was undertaken in the US more than 50 years ago. However, the long term outcomes of the Cambridge-Somerville project show the potential for an intervention like the Troubled Families Programme to cause harms. Weak evaluations of the Family Intervention Project cannot rule out the possibility of similar outcomes.

What would a more adequate response involve? If the government wants to foster healthy parenting skills and prevent youth problem behaviours, a substantial UK and international evidence base suggests this should involve effective parenting programmes that target 3-8 year olds.<sup>6</sup> These interventions can be delivered to families in need (not only those deemed to be troubled) within community based settings, such as children's centres.<sup>7</sup> Evidence suggests that functional family therapy and multisystemic therapy are effective at reducing youth offending,<sup>8</sup> including in UK settings.

However, even these evidence based interventions may not be able to reach all in need and may be insufficient to achieve substantial effects at the population level<sup>9</sup>; they should therefore be complemented with universal interventions. Good evidence exists for a variety of universal school based interventions to challenge disengagement and underachievement, such as changing how teachers interact with students and enhancing social and emotional learning.<sup>10 11</sup> However, the extent to which these interventions might be feasible and effective in England is likely to be undermined by recent changes in education policy. Ofsted, the schools inspectorate, is no longer required to assess schools on the extent to which they promote student wellbeing, and the previous National Healthy Schools Programme has been abandoned. Furthermore, there is evidence that a strong focus on high stakes tests and league tables may reduce the attention that schools give to the most disadvantaged students and exacerbate educational inequalities.<sup>12</sup>

The Troubled Families Programme may be an eye catching populist response to the riots, but obliging troubled families to accept a non-negotiable non-evidence-based intervention is unlikely to prevent future disorder and may well produce unintended harms. Policy makers should focus instead on a combination of evidence based, targeted, and universal interventions and ensure that the broader policy environment supports these.

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News: Anonymised data of all NHS treatments must be put in public domain by 2015, strategy says (BMJ 2012;344:e3648)

## The new NHS information strategy

It rewrites the rules on medical records: the presumption is sharing

NHS Information Strategy proposals and responsibilities of the main stakeholders	
Stakeholder	Main proposals
Clinicians	All: always use the NHS number; use NHS mail accounts and other tools to facilitate secure communication “where cost effective”
	GPs: make access to personal records, appointment booking, repeat prescriptions, and “communication with the practice” available securely online to patients by 2015
Patients and citizens	Access own personal GP record online by 2015 and other records “as information technology systems allow”
	Choose people to help patients interpret their records (and with whom their record can be shared to allow this)
Social care professionals	For publicly funded social care (including social enterprises and any qualified providers, except small voluntary organisations), all personal data must be identified using the NHS number by 2015
NHS provider organisations	Appoint information champions; make data available to other authorised users with or without NHS number attached for linkage as appropriate
Clinical commissioning groups	Commission support to help people navigate and use information; drive local delivery of this information strategy
NHS Commissioning Board and Department of Health	Set out more detailed implementation plans; set information standards. Commission an independent review of information governance led by Dame Fiona Caldicott; commission Health and Social Care Information Centre to collect information for health and social care. Stop providing information where this is better done by the market—for example, show patient comments “from a number of routes”
Royal colleges, Academy of Colleges	Provide professional leadership on information governance and management, terminology, and coding. For example, the Royal College of Physicians could continue to work on record keeping standards; the Royal College of General Practitioners could develop proposals for roll out of patient access to GP records
Health and Social Care Information Centre	Collect, hold securely, link, and make readily available data in safe, de-identified formats; act as focal point for information across health and care sectors; publish a register of the information collected by itself and other organisations
Industry	Intellect (trade association) to develop an “evidence case” for a portal approach to secure viewing of health and care records online by patients and professionals
Researchers	Access to NHS data via a simpler portal and permissions
Other bodies	Health Education England: ensure education and training are in place to support this strategy
	Medicines and Healthcare Products Regulatory Agency: lead on using information to support research and life sciences
	Local authorities: plan to help the NHS achieve this vision, appoint local champions
	Health and wellbeing boards: influence the use of information and provide support for people to make better use of information so that the burden on local services is reduced
	Public Health England: set out implementation plans to achieve this vision in public health; set information standards and commission Health and Social Care Information Centre to collect public health information, working with registries and observatories

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Commentators rarely accuse the current UK government of lacking ambition over NHS reforms, but many have complained that its new information strategy, *The Power of Information*,<sup>1</sup> contains simply platitudes. Some dismiss the strategy’s calls for a culture change, claiming that no change in professional culture is needed because doctors, nurses, and others are already tweeting and using apps to shape their personal lives via social media. But on close inspection the culture change required does not relate to how we use technology but to how we share and use information.

**[To] change . . . the way we view records and share the data they contain [the record] must change into a document written for others to read, using language and codes predictably organised**

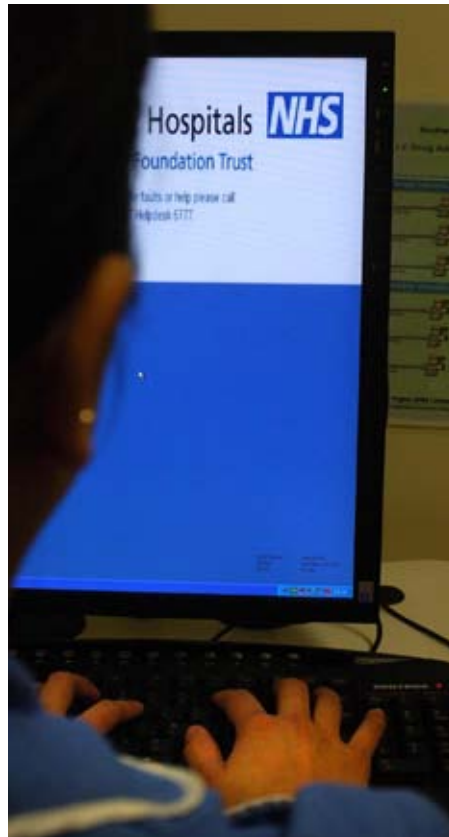
The table lists some of the main proposals and how they affect different stakeholders. Of these the most revolutionary are sharing patient data with all health and social care professionals who need it; patients’ access to their primary care records by 2015; and anonymous data being used by the NHS, researchers, and industry to promote quality and innovation. Together, these add up to a fundamental change in the ways we view records and share the data they contain.

The first challenge is a presumption that professionals should share records across organisations to improve safety, efficiency, and outcomes. Most patient records now are an informal aide mémoire, full of quirky individualism and undefined local practice governing how words, phrases, and codes are used. So that the record can be understood by all, it must change into a document written for others to read, using language and codes predictably organised under standard headings agreed on by the professions.

Getting agreement for a standard record structure across all health and social care

professions sounds hard but was achieved in the 1998 Headings Programme.<sup>2</sup> The pioneering work of the Royal College of Physicians' informatics unit on standard record contents for hospital discharge letters and inpatient transfer,<sup>3</sup> and of the Royal College of General Practitioners' informatics group on record sharing,<sup>4</sup> are also important. They remind us that information technology is not the issue: the focus must be on which decisions doctors, nurses, and other professionals make in different settings and what information they need to support these decisions.<sup>5</sup> Information is "organised data or knowledge used to support decisions,"<sup>6</sup> so people, not computers, come first when it is being agreed which information to record and communicate. Professional bodies still need to tackle hard problems like the nature of a "diagnosis" or a "problem"—or even when to use labels like "cigarette smoker." Does this mean someone who stopped last month, smokes two cigarettes a week, or uses electronic cigarettes?<sup>7</sup> However, as long as well informed health and care professionals, people from health informatics,<sup>8</sup> and the royal colleges collaborate on creating standards for records, we will soon realise an agreed language of care and ways to represent it using computers<sup>5 7</sup>—and that must bring safer, more efficient practice.

We should also take heart about the second challenge—of patients accessing their general practitioner record by 2015. From the strategy's subtitle "Putting all of us in control of the health and care information we need" onwards, the author of this strategy uses personal pronouns—for example, "our information," "my records." By arguing from the patient-citizen's viewpoint, this strategy shifts the emphasis from grandiose national technology programmes to liberating information to support professionals and patients in particular.<sup>9</sup> The technical challenge of making a general practice record electronically accessible by 2015 while keeping it secure is small compared with the cultural challenge for all clinicians of using patient appropriate language in the record. This language needs to inform and reassure the public, so that personal record access reduces, rather than increases, general practice consultation rates—as is assumed in the accompanying business case. Some general practitioners and hospital doctors are already exploring this. For example, in Stoke on Trent chest and diabetes physicians in some



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**By arguing from the patient-citizen's viewpoint [the] strategy shifts the emphasis from grandiose national technology programmes to liberating information to support professionals and patients**

clinics now routinely dictate letters to the patient, with a copy to the general practitioner. More surprisingly, they dictate in front of the patient, giving the patient a chance to reword if necessary. It takes time and confidence to do this, but this example suggests how we must all change.

The final challenge is that data will be routinely aggregated, anonymised, and used by the NHS, researchers, and—most contentiously—industry to promote quality and research. This has already been announced in another NHS strategy, *Innovation, Health and Wealth*,<sup>10</sup> and will require another culture change, from the libertarian "My personal data exist for my care only" to the near Maoist "Personal data do not exist; society needs the benefits from research on records." This shift sounds unlikely, but Brussels is also consulting on its new Data

Protection Regulation, which is built on the utilitarian principle of the greatest benefit for the greatest number. It is hard to predict how fragmented NHS organisations gingered up by privacy advocates will resolve this, but other powerful interests are also active here, including the Treasury, industry, and research funders such as the National Institute for Health Research, Medical Research Council, and the Wellcome Trust—all galvanised by the success of the Cabinet Office's open data initiative.

We live in times where small policy changes and timely lobbying can prompt big changes in public services. This NHS information strategy might stimulate the Patients Association to ally with the Long Term Conditions Alliance, Age UK, and the UK Clinical Research Collaboration to bring pressure on royal colleges, software vendors, Caldicott guardians, and even the BMA to open up records. And that really could be an information revolution.

**Competing interests:** The author has completed the ICMJE uniform disclosure form at [www.icmje.org/coi\\_disclosure.pdf](http://www.icmje.org/coi_disclosure.pdf) (available on request from the corresponding author) and declares: he was a consultant to the Headings programme and is a member of the Department of Health Task and Finish group on Digital by Default, has a very small equity stake in Medix, a medical ISP, NHS Midlands and East SHA supports the Institute of Digital Healthcare; no other financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

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

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