Editor's choice

*Editor's choice: FAffing about*
Tony Delamothe
BMJ 2007;334, doi:10.1136/bmj.39259.443646.47

*US editor's choice: The side effects of "P4P"*
Douglas Kamerow
BMJ 2007;334, doi:10.1136/bmj.39260.443970.3A

Editorials

*Reducing the length of time between HIV infection and diagnosis*
Catherine Dodds, Peter Weatherburn

*Ethics of collecting and using healthcare data*
Derick Wade
BMJ 2007;334:1330-1331, doi:10.1136/bmj.39247.679329.80

*Lactose intolerance*
Shinjini Bhatnagar, Rakesh Aggarwal
BMJ 2007;334:1331-1332, doi:10.1136/bmj.39252.524375.80

*Performance measurement and equity*
Arlene S Bierman, Jocalyn P Clark
BMJ 2007;334:1333-1334, doi:10.1136/bmj.39251.660127.AD

*Involving patients in the BMJ*
Peter Lapsley, Fiona Godlee
BMJ 2007;334:1334, doi:10.1136/bmj.39246.621088.80

Letters

*This week’s letters*

<MTAS: Mental health of applicants seems to be deteriorating>
Gregory J Lydall, Amit Malik, Dinesh Bhugra
BMJ 2007;334:1335, doi:10.1136/bmj.39254.905764.1F

*Cosmetic genitoplasty: It's female genital mutilation and should be prosecuted*
Marge Berer
BMJ 2007;334:1335, doi:10.1136/bmj.39252.646042.3A
Imaging peripheral disease: Gadolinium contrast may be risky in kidney disease
Peter C Thomson, Tara A Collidge, Patrick B Mark, Jamie P Traynor
BMJ 2007;334:1335-1336, doi:10.1136/bmj.39254.924641.1F

What about the GPs?: We help treat acute coronary syndromes
Hasnain M Dalal
BMJ 2007;334:1336, doi:10.1136/bmj.39254.922350.1F

What about the GPs?: We're still great for continuity
John Sharvill
BMJ 2007;334:1336, doi:10.1136/bmj.39254.920706.1F

NHS independence: An NHS board is the way forward
Layla Jader
BMJ 2007;334:1336, doi:10.1136/bmj.39254.931053.1F

News

BMA annual representative meeting, Torquay, 25 June to 29 June:
Doctors call for England's chief medical officer to resign over "NHS in crisis"
Zosia Kmietowicz
BMJ 2007;334:1337, doi:10.1136/bmj.39258.575625.DB

NICE's decision on dementia drugs was "irrational," High Court is told
Clare Dyer
BMJ 2007;334:1337, doi:10.1136/bmj.39259.403171.DB

US health professionals demonstrate in support of Sicko
New York

Tories want to free NHS of political interference
Michael Day
BMJ 2007;334:1338, doi:10.1136/bmj.39255.541308.DB

More recruitment from ethnic minority groups would improve NHS's service, report says
Seye Abimbola
BMJ 2007;334:1339, doi:10.1136/bmj.39258.431852.DB

Class action over Abbott's pricing of antiretroviral moves forward
Bob Roehr
BMJ 2007;334:1339, doi:10.1136/bmj.39257.587569.BE

In Brief: News

BMJ 2007;334:1340, doi:10.1136/bmj.39258.417500.DB

WHO launches plan to fight drug resistant tuberculosis
Peter Moszynski
BMJ 2007;334:1340-1341, doi:10.1136/bmj.39255.559653.DB

Aid workers are compromised by "war on terror," UN official says
Peter Moszynski
BMJ 2007;334:1340, doi:10.1136/bmj.39259.364201.DB
Clinical trial results often overstate benefits of treatment
Michael Day
BMJ 2007;334:1341, doi:10.1136/bmj.39259.392523.DB

Social measures may control pandemic flu better than drugs and vaccines
Richard Smith
BMJ 2007;334:1341, doi:10.1136/bmj.39255.606713.DB

Government compromises on mental health bill
Clare Dyer
BMJ 2007;334:1342, doi:10.1136/bmj.39258.566655.DB

Human rights groups plead for protection for hospital patients in Gaza
Merav Sarig
BMJ 2007;334:1342, doi:10.1136/bmj.39259.392575.DB

BMA annual representative meeting, Torquay, 25 June to 29 June:
Public backs the idea of an independently run NHS
Zosia Kmietowicz
BMJ 2007;334:1343, doi:10.1136/bmj.39258.618889.DB

BMA annual representative meeting, Torquay, 25 June to 29 June:
Public should be told that rationing is inevitable, say doctors
Zosia Kmietowicz
BMJ 2007;334:1343, doi:10.1136/bmj.39258.662083.DB

BMA annual representative meeting, Torquay, 25 June to 29 June:
Choice for patients can worsen quality of care
Andrew Cole
BMJ 2007;334:1343, doi:10.1136/bmj.39259.472396.DB

BMA annual representative meeting, Torquay, 25 June to 28 June:
BMA calls for action on "epidemic" of alcohol related problems
Andrew Cole, Zosia Kmietowicz
BMJ 2007;334:1343, doi:10.1136/bmj.39259.668565.DB

Afghan farmers should be licensed to grow poppies for morphine, Senlis Council says
Owen Dyer
BMJ 2007;334:1343, doi:10.1136/bmj.39259.472396.DB

NHS is told it must play its part in tackling climate change
Adrian O'Dowd
BMJ 2007;334:1343, doi:10.1136/bmj.39258.584734.DB

Long haul flights double the risk of thrombosis related to air travel
John Zarocostas
BMJ 2007;334:1343, doi:10.1136/bmj.39259.479063.DB

BMA annual representative meeting, Torquay, 25 June to 29 June:
BMA rejects call for parents of obese children to be charged with neglect
Andrew Cole and Zosia Kmietowicz
BMJ 2007;334:1343, doi:10.1136/bmj.39259.602245.DB
BMA annual representative meeting, Torquay, 25 June to 29 June:
**Raise price of alcohol in Scotland to combat disease, BMA says**
Zosia Kmietowicz
BMJ 2007;334:1343, doi:10.1136/bmj.39258.499167.DB

BMA annual representative meeting, Torquay, 25 June to 29 June:
**Members say BMA's green paper is too "polite"**
Andrew Cole
BMJ 2007;334:1343, doi:10.1136/bmj.39259.377037.DB

BMA annual representative meeting, Torquay, 25 June to 29 June:
**BMA calls for end of discrimination against women in medical academia**
Andrew Cole
BMJ 2007;334:1343, doi:10.1136/bmj.39259.436053.DB

Drug treatment is proposed to manage child sex offenders
Owen Dyer
BMJ 2007;334:1343, doi:10.1136/bmj.39257.583310.BE

NHS Direct could be a useful early warning system for respiratory infections
Roger Dobson
BMJ 2007;334:1343, doi:10.1136/bmj.39257.585405.BE

**Shortcuts from other journals:** *It's not what you say but how you say it*
BMJ 2007;334:1344, doi:10.1136/bmj.334.7608.1344

**Shortcuts from other journals:** *Survival trends look worrying for women with diabetes*
BMJ 2007;334:1344, doi:10.1136/bmj.39255.386053.AD

**Shortcuts from other journals:** *Nephrology patients deserve better evidence*
BMJ 2007;334:1344, doi:10.1136/bmj.334.7608.1344-b

**Shortcuts from other journals:** *Childhood multiple sclerosis is distinct from adult disease*
BMJ 2007;334:1344-1345, doi:10.1136/bmj.334.7608.1344-c

**Shortcuts from other journals:** *Alcohol is killing Russian working men*
BMJ 2007;334:1345, doi:10.1136/bmj.334.7608.1345

**Shortcuts from other journals:** *Oestrogen-only HRT prevents coronary artery calcification in younger women*
BMJ 2007;334:1345, doi:10.1136/bmj.334.7608.1345-a

**Shortcuts from other journals:** *The end of the line for guinea worm*
BMJ 2007;334:1345, doi:10.1136/bmj.334.7608.1345-b
Shortcuts from other journals: First patients have gene therapy for Parkinson's disease
BMJ 2007;334:1345, doi:10.1136/bmj.334.7608.1345-c

Feature
HIV research: Quest for the AIDS vaccine
Alison Tonks
BMJ 2007;334:1346-1348, doi:10.1136/bmj.39240.416968.AD

Observations
Body politic: Collision, collusion, and confusion
Nigel Hawkes
BMJ 2007;334:1349, doi:10.1136/bmj.39255.707488.94
Richard Granger's legacy: Computer says yes—and no
Michael Cross
BMJ 2007;334:1350-1351, doi:10.1136/bmj.39259.445035.34
What's on bmj.com: Protecting vulnerable populations
Birte Twisselmann
BMJ 2007;334:1351, doi:10.1136/bmj.39258.706157.3A

Analysis
Time to move towards opt-out testing for HIV in the UK
M Hamill, K Burgoine, F Farrell, J Hemelaar, G Patel, D E Welchew, H W Jaffe
BMJ 2007;334:1352-1354, doi:10.1136/bmj.39218.404201.94
Routine testing to reduce late HIV diagnosis in France
Cyrille Delpierre, Lise Cuzin, France Lert
BMJ 2007;334:1354-1356, doi:10.1136/bmj.39225.458218.94

Research
Impact of financial incentives on clinical autonomy and internal motivation in primary care: ethnographic study
Ruth McDonald, Stephen Harrison, Kath Checkland, Stephen M Campbell, Martin Roland
Implementing the NHS information technology programme: qualitative study of progress in acute trusts
Jane Hendy, Naomi Fulop, Barnaby C Reeves, Andrew Hutchings, Simon Collin

Clinical review
Driving and dementia
David A Breen, David P Breen, John W Moore, Patricia A Breen, Desmond O'Neill
BMJ 2007;334:1365-1369, doi:10.1136/bmj.39233.585208.55
Practice
NICE guidelines: Management of faecal incontinence in adults: summary of NICE guidance
Christine Norton, Louise Thomas, Jennifer Hill, Guideline Development Group
BMJ 2007;334:1370-1371, doi:10.1136/bmj.39231.633275.AD

Interactive case report: A patient with suspected miscarriage is found to have hypertension, renal failure, and thrombocytopenia: case presentation
Chris M Laing, Rhys Roberts, Liz Lightstone, Alison Graham, Terry H Cook, Shaun Summers, Charles D Pusey
BMJ 2007;334:1372, doi:10.1136/bmj.39212.564745.BE

Views & reviews
Personal views: How to avoid an e-headache
Joan S Ash
BMJ 2007;334:1373, doi:10.1136/bmj.39252.490880.80

Netlines
Harry Brown
BMJ 2007;334:1374, doi:10.1136/bmj.39259.500255.94

Review of the week: Sex and drugs and rock and roll
Colin Martin
BMJ 2007;334:1374-1375, doi:10.1136/bmj.39258.502153.59

From the frontline: Talk the talk
Des Spence

The bigger picture: Africa
Mary E Black
BMJ 2007;334:1376, doi:10.1136/bmj.39258.505637.59

Between the lines: Reality bites
Theodore Dalrymple
BMJ 2007;334:1377, doi:10.1136/bmj.39258.525359.59

Medical classics: The Diving-Bell and the Butterfly
David Warriner
BMJ 2007;334:1377, doi:10.1136/bmj.39239.635463.4E

Obituaries
This week’s obituaries
George Douglas Pinker
Alasdair Fraser, Frank Loeffler

Russell John Boyd
Bernard A Foëx, Simon D Carley
BMJ 2007;334:1379, doi:10.1136/bmj.39245.810903.BE

Glyn Ieuan Tegeryn Griffiths
Mary Anne Griffiths, Barbara Griffiths
BMJ 2007;334:1379, doi:10.1136/bmj.39246.667188.BE
Lawrence Gordon Jubb
Ronald Jubb
BMJ 2007;334:1379, doi:10.1136/bmj.39246.651921.BE

Thomas Edwin Moody
Thomas Laurence Moody, John Kirkpatrick
BMJ 2007;334:1379, doi:10.1136/bmj.39251.664051.AD

Robert James Sanderson
Gillian MacDougall, David Sim, Paul Sanderson, Christine Tolsma
BMJ 2007;334:1379, doi:10.1136/bmj.39251.641875.AD

William Todd
John Todd
BMJ 2007;334:1379, doi:10.1136/bmj.39244.618831.BE

Philippa Mary Bruce White
Margaret Sillis, Helen Williams, Judith Richards
BMJ 2007;334:1379, doi:10.1136/bmj.39244.706690.BE

Minerva

BMJ 2007;334:1380, doi:10.1136/bmj.39255.502627.BE1

Minerva
Vidhya Nagaratnam, Jeremy Howard
BMJ 2007;334:1380, doi:10.1136/bmj.39255.502627.BE

Fillers

Endpiece: Placebo

BMJ 2007;334:1359, doi:10.1136/bmj.39195.506921.BD

Career focus

Read this week's articles on
Reducing the length of time between HIV infection and diagnosis

Targeting high risk groups should remain the priority

In this week’s *BMJ*, two analysis articles about testing for HIV argue for changes in policy that would expand the number of people routinely tested by promoting opt-out approaches. Both papers argue that this would increase the proportion of the population who know their serostatus and would decrease the number of late diagnoses of HIV. The papers agree about the benefits of swift diagnosis of HIV, including reduced mortality and morbidity, less onward transmission because treatment should reduce infectiousness, and reduced costs of acute treatment and lost productivity.

We argue that a more precise goal for any changes in policy should be to reduce the average time between HIV infection and diagnosis in people who become infected. This goal allows a range of measures of success beyond a CD4 count below 200×10⁹/l and acknowledges that the earlier HIV is diagnosed the better.

As the secretary general of the United Nations highlights, improved epidemiological outcomes are dependent on people being able to test in “a social and legal environment that is supportive and safe.” This needs to apply equally to people who receive a negative result as those who do not. Many of the benefits of having HIV diagnosed are not available to people without legal status in the United Kingdom because of the costs of drugs and continuing care. In addition to questions of access to treatment, a diagnosis of HIV has implications for sexual and social relationships, especially in the light of criminal prosecutions for the reckless transmission of HIV.

HIV is one of the most stigmatised diseases. This stigma is embedded in pre-existing social inequality, and it is disappointing that neither analysis article takes account of the extent to which racism, xenophobia, and homophobia drive HIV related stigma. Huge increases in the number of people testing negative for HIV will not change those attitudes or the practices that maintain the social inequalities that reinforce HIV related stigma.

This call for expansion of routine opt-out HIV testing encompasses primary care and various acute settings. However, studies in the UK show that health professionals in non-HIV specialist settings discriminate against people with HIV. Opt-out testing policies would exacerbate this, and substantial investment in training and staff support would be needed to foster a “safe and supportive” environment as stipulated by the UN.

While calls for seroprevalence studies that are not linked to named individuals and a further examination of cost effectiveness are welcome, it is unclear what justification these could provide for expanded routine opt-out HIV testing. It is unlikely that the Centers for Disease Control (CDC) threshold for universal testing—when there is a 0.1% prevalence of HIV in a given population—would be reached in many healthcare settings. While opt-out HIV testing in antenatal care is widely regarded as a success, it did not reach this threshold in England and Scotland in 2005. Moreover, a recent analysis of CDC guidelines suggests that counselling and testing that is targeted at populations most likely to have undiagnosed HIV would diagnose more HIV infections, prevent more HIV infections, and do this at a lower cost for each infection averted than would opt-out testing without specific consent or pre-test discussion.

In the UK in 2005, 20 100 people were assumed to have undiagnosed HIV. Most were assumed to be men who have sex with men (9000), African born heterosexuals (5400), or people who inject drugs (500). Only 4900 were thought to be non-African born heterosexuals who do not inject drugs. With a relatively small number of undiagnosed people in the population—mainly in groups where access to healthcare services can be problematic—expanding HIV testing provision across a range of settings is unlikely to be cost effective. If such an expansion requires the omission of pre-test discussion, then this conflicts with UK national guidelines on HIV testing, especially for people at highest risk, who constitute three quarters of those with undiagnosed HIV. It also conflicts with evidence from a CDC sponsored randomised control trial that interactive client centred counselling during HIV testing could reduce subsequent risk behaviour and the incidence of sexually transmitted infections.

Since the publication of the national strategy for sexual health and HIV, uptake of HIV testing by people attending UK genitourinary medicine clinics has increased yearly. In 2005, 80% of men who have sex with men were tested, compared with 61% in 2001, and 82% of heterosexuals were tested compared with 41%. While some people with undiagnosed HIV still attend these clinics without being tested, the proportion of UK residents with undiagnosed HIV has fallen yearly as the proportion of people who are tested for HIV at a sexual health clinic has risen.

Factors that influence the offer and uptake of HIV testing and whether patients return for the results include the sexual health clinic’s policy on HIV testing (opt-in or opt-out) and how long people have to wait for results.
Opt-out HIV testing is not a universal policy in genitourinary medicine clinics in the UK, even for African migrants and men who have sex with men. Moreover, waiting times for appointments and HIV test results vary and point of care (rapid) testing is relatively rare.

These data show that the possibilities for targeting and diagnosing people at highest risk of HIV have not been exhausted. Intensified targeting is challenging but is essential for a major impact on the time between infection and diagnosis. If this strategy proves effective we could then consider how to encourage HIV testing in people who are less likely to have HIV.


Ethics of collecting and using healthcare data

Primary responsibility lies with the organisations involved, not ethical review committees

Quality assurance is a broad concept that includes activities termed audit, quality improvement, and clinical governance. Both quality assurance and research require the systematic collection and analysis of data from all (relevant) patients. However, whereas research activities are generally required to undergo independent ethical review, audit activities are exempt from such review. How can we ensure that quality assurance activities are ethical?

Patients using any healthcare system have an ethical responsibility to help with quality assurance activities, and with epidemiological research based on population-wide databases, such as the United Kingdom’s new National Health Service programme, because they will benefit from such activities. However, involvement in quality assurance and epidemiological research usually involves using patients’ data without their consent. In return for this loss of autonomy and potential risk (of disclosing information that might harm), patients should expect quality assurance activities to be ethically sound, healthcare resources to be committed to quality assurance, and benefits to justify any risks and burdens.

Two national working parties, in the United States and Australia, have considered the ethics of quality assurance activities. The US Hastings Center report considers that research activities can be distinguished from quality assurance and suggests that organisations take responsibility for the ethics of their own quality assurance. In contrast, the Australian report agrees with many others that the distinction is not possible, and it suggests that research ethics committees should be approached when potential ethical problems exist.

Data protection laws make the resolution of this problem urgent. Quality assurance may be stopped, unethical activities may occur, and research may be relabelled as quality assurance to avoid scrutiny, especially because the existing research ethics framework is becoming increasingly overwhelmed, often delaying or preventing research.

The ethical problem associated with the collection and use of data for non-clinical purposes relates to the relationship between patients as a group and organisations (such as clinical teams, whole hospitals). It is assumed that most ethical issues will arise in the context of research, while other activities in healthcare organisations are automatically ethical. This assumption has led to attempts to categorise research separately from other activities. However, these assumptions are invalid; healthcare organisations are no more or less likely than researchers to pursue ethically dubious activities. We should therefore ask ourselves how to ensure that the collection and analysis of data from patients within health care is carried out ethically.

Collecting and using patient generated data, beyond simply making an individual clinical decision, is ethically sound only if there is (or could reasonably arise) a question to be answered; the methodology (design, data collected, etc) will answer the question; and the costs, including both communal healthcare resources and any risks and burden imposed on the participants, justify the benefits to society. Asking the questions in the box will help to identify the nature and extent of any ethical concern.

But who should ask the questions, and who should make the ethical judgment? The Hastings Center report argues convincingly that institutional review boards as a...
single external ethical “hurdle” are an inappropriate way of achieving ethical standards in quality assurance.2

Instead, the authors recommend that “the primary responsibility for the ethical conduct of quality improvement be lodged in individual organisations . . . [it] should be integrated into normal supervision and management, with the organisation’s leaders [being] responsible for seeing that the integration occurs and is effective.” There is no reason why this recommendation could not also apply to all activities within health care, including research.13

Ethically difficult situations that require independent help will still arise. Existing ethical review committees could provide independent advice,1 but only if their total workload is reduced. This could be achieved if ethical problems were considered in proportion to the importance of the ethical problem.3 6 7 12 We need an ethical ladder to lift us over problems, not an ethical hurdle to hinder people undertaking research. Organisations should have internal procedures for ensuring their activities are ethical, and they should seek external help only when it is needed.

Finally, we need to check that organisations are taking their ethical responsibilities seriously.4 The professional, personal, and organisational responsibilities for ethical behaviour should be made explicit, and organisations need to incorporate ethical considerations into all management activities. Their performance of this duty should be reviewed by external monitoring and accrediting agencies.2

In summary, the ethical responsibility of systematic collection and analysis of patient data for any purpose is the responsibility of the people and organisations involved. Internal organisational arrangements should allow most problems to be resolved but when they are complex or difficult, external help should be sought from an accredited source, such as ethics review boards. External accrediting organisations should audit ethical review procedures as they audit other aspects of an organisation.

4 Mayor S. NHS IT system must use unique patient identifiers to achieve research potential. BMJ 2007 doi: 10.1136/bmj.39245.392523.DB.
12 Jamrozik K. Research ethics: what is the plot we seem to have lost? BMJ 2004;329:286-7.

Lactose intolerance
Is common and can be diagnosed clinically and treated with simple dietary measures

Lactose intolerance occurs in about 25% of people in Europe; 50-80% of people of Hispanic origin, people from south India, black people, and Ashkenazi Jews; and almost 100% of people in Asia and American Indians.1 Lactose is a disaccharide sugar that is found exclusively in mammalian milk and is digested by the enzyme lactase in the mucosal brush border of the intestine. Reduced intestinal lactase results in malabsorption of lactose. The unabsorbed lactose is metabolised by colonic bacteria to produce gas and short chain fatty acids, causing the clinical syndrome of abdominal cramps, bloating, diarrhoea, and flatulence. Lactose malabsorption does not always cause lactose intolerance; symptoms depend on the amount and rate of lactose reaching the colon, and the amount and type of colonic flora.

Lactase deficiency may be classified as primary, secondary, congenital, and developmental. The classification is important as it relates to diagnosis, prognosis, and treatment. In all mammals, lactase concentrations are at their highest shortly after birth and decline rapidly after the usual age of weaning. In people with primary lactase deficiency, such a physiological decline in lactase concentrations occurs at the age of weaning. This condition is a recessive inherited trait; the underlying genetic change is different in the European and African populations.2 3 Secondary lactase deficiency results from injury to the

---

BMJ 2007;334:1331-2
doi:10.1136/bmj.39252.524.375.80

Lactose is a disaccharide sugar that is found exclusively in mammalian milk and is digested by the enzyme lactase in the mucosal brush border of the intestine. Reduced intestinal lactase results in malabsorption of lactose. The unabsorbed lactose is metabolised by colonic bacteria to produce gas and short chain fatty acids, causing the clinical syndrome of abdominal cramps, bloating, diarrhoea, and flatulence. Lactose malabsorption does not always cause lactose intolerance; symptoms depend on the amount and rate of lactose reaching the colon, and the amount and type of colonic flora.

Lactase deficiency may be classified as primary, secondary, congenital, and developmental. The classification is important as it relates to diagnosis, prognosis, and treatment. In all mammals, lactase concentrations are at their highest shortly after birth and decline rapidly after the usual age of weaning. In people with primary lactase deficiency, such a physiological decline in lactase concentrations occurs at the age of weaning. This condition is a recessive inherited trait; the underlying genetic change is different in the European and African populations.2 3 Secondary lactase deficiency results from injury to the
small bowel mucosal brush border secondary to viral or non-viral intestinal infection. It is more common in children, particularly those in developing countries, where such infections are common. Congenital lactase deficiency is an extremely rare disorder that manifests at birth, soon after milk is introduced. Affected infants have minimal or absent lactase in an otherwise normal intestinal mucosa. Developmental lactase deficiency occurs in premature infants (<34 weeks' gestation), and rapidly improves as the intestinal mucosa matures.

Lactose intolerance should be suspected in people with abdominal symptoms after ingestion of milk and milk products. The symptoms can be disabling enough to interfere with daily life. Improvement in symptoms after eliminating such foods and worsening when they are reintroduced confirms the diagnosis. Diarrhoea is more pronounced in children with secondary lactase deficiency than in those with the primary form and may lead to dehydration and growth failure; perianal excoriation due to acidic stools are common.

Several tests are available for the diagnosis of lactose malabsorption. The lactose tolerance test (reproduction of symptoms and rise in serum glucose by <1.11 mmol/l, 60-120 minutes after ingestion of 50 g lactose) has a sensitivity of around 75%. The lactose hydrogen breath test (increase in hydrogen concentration in exhaled air to >20 parts per million after 20 g of lactose) is more sensitive. A breath test using carbon-13 labelled lactose and estimation of lactase in intestinal biopsy are also available. However, the diagnosis can be made easily on the basis of clinical history by general practitioners as well as specialists, and diagnostic tests are rarely needed in clinical practice. Differences in underlying genetic changes in different geographical regions may predict the development of a single DNA based diagnostic test.

Treatment depends on the underlying type of deficiency. In primary lactase deficiency, the development of symptoms depends on how much lactose needs to be ingested before the available lactase is saturated. Thus, most people with primary lactase deficiency can ingest up to 240 ml of milk (12 g of lactose) without developing symptoms. It may help to divide daily milk intake into several small portions and to take it with other foods. Yogurt, curds, and cheeses are better tolerated, because lactase is partially hydrolysed by bacteria during their preparation and gastric emptying is slower as these products have a thicker consistency. Lactase enzyme preparations—ingested directly or added to milk—and soya milk have been used. These are too costly for people in poorer countries, however, and are possibly unnecessary. Instead, people with lactose intolerance should be encouraged to gradually increase their intake of milk—this causes changes in the intestine that permit higher milk intake. Milk is the main source of calcium in predominantly vegetarian communities, so ingestion of milk is important to avoid the increased risk of osteopenia, osteoporosis, and long bone fractures. Milk-cereal mixtures delay the entry of lactose into the intestine, permitting better absorption. Since these are cheap and easily prepared at home, their use should be promoted.

In secondary lactase deficiency, treatment is directed at the underlying cause. Short periods of lactose intolerance are common after episodes of infective diarrhoea and may prolong the diarrhoeal illness. This can lead to unnecessary antimicrobial treatment and unwarranted avoidance of milk—a meta-analysis has shown that most children with acute diarrhoea can safely continue to receive breast or undiluted animal milk. This is particularly important in developing countries, where milk is a convenient, readily available, and well accepted food of exceptional nutritional value. A randomised trial in malnourished children in India found that giving milk rather than yoghurt during acute diarrhoea was associated with higher milk intake and better weight gain and did not increase diarrhoea. Further randomised controlled trials have shown that milk-cereal mixtures given at frequent intervals (nearly 2 g/kg/day of lactose or 40 ml/kg/day of milk) were well tolerated by most children with persistent diarrhoea.

Lactose intolerance is a common condition that can be diagnosed on clinical history and treated with simple dietary measures. Most patients do not need referral to a specialist or diagnostic laboratory tests. Non-responders will benefit from reducing lactose intake below their current threshold of tolerance, followed by long term steps directed at improving adaptation of the intestine.

Performance measurement and equity

To maximise benefits and minimise harm, equity must be built in from the start

Performance measurement is now a reality for clinicians around the world. It involves measuring and monitoring quality of care using standardised indicators. Shortcomings in the quality of care—the gap between what we know and what we do—are well documented. So too are inequities in access, quality, and outcomes linked to gender, ethnic origin, and socioeconomic status. Recognition of substandard and uneven quality of care has fuelled calls for providers to be more publicly accountable and for health systems to change.

Interest is growing in performance measurement as a way to drive improvements in health care. In this week’s BMJ, McDonald and colleagues describe an ethnographic case study in which two English general practices changed their organisation to achieve high performance scores under the quality and outcomes framework. The quality and outcomes framework, and other high profile measurement and reporting efforts such as those in the US Veterans’ Health Administration, have met with some early success. Adding to this enthusiasm is a recent study that attributes declining mortality from acute coronary syndromes and heart failure—two conditions in which performance measurement has been widely used—to increased use of evidence based treatments. However, optimism about potential benefits is tempered by growing concerns about potential harms.

McDonald and colleagues were particularly concerned with adverse effects on practitioners’ clinical autonomy and motivation. However, they found that incentives were mostly aligned with professional values about optimising quality of care. What the study does not tell us, though, is how these organisational changes were perceived by patients or what impact they had on patients from different communities in different practice settings.

So far, disadvantaged patients may stand to benefit most from structured efforts to measure and improve quality, as they often experience the largest quality gaps. Importantly, however, they may also be at greatest risk of harm. Equity is a major dimension of healthcare quality and a key attribute of high performing health systems, so initiatives to improve quality will be incomplete unless inequities are reduced as performance improves. Performance measurement and quality improvement alone will not result in more equitable systems of care.

Interventions to improve quality can impact on health inequities in three ways: they may narrow, maintain, or widen existing inequities, depending on their relative effectiveness in different groups of people and how they deal with the root causes of inequity. In a randomised controlled trial, a complex intervention designed to improve the quality of primary care for depression reduced disparities by improving health outcomes and unmet need significantly more among Latinos and African Americans than among whites.

A longitudinal study examined the impact of performance measurement for patients with end stage renal disease insured by Medicare in the United States. It found that racial and gender disparities were reduced in relation to the adequacy of haemodialysis but were unchanged for the management of anaemia and nutritional status. A retrospective analysis of performance data from Medicare managed care showed steady improvement over many years, with narrowing of disparities in process indicators. Control of glucose and cholesterol improved in both white patients and black patients. However, racial disparities in outcome measures widened because the improvements were greater for white patients. This shows that it is more difficult to improve outcomes than processes of care for disadvantaged populations.

If we are to identify persistent disparities between populations that will otherwise be masked by overall gains in quality, we need performance measures that are stratified by sex, ethnic origin, or socioeconomic status. In Canada, the project for an Ontario women’s health evidence based report card (POWER) is developing explicit methods for assessing equity as a routine part of performance measurement.

In the US and the UK, practices that serve socioeconomically disadvantaged patients have shown poorer performance on commonly used quality indicators than have practices serving more advantaged patients. Reporting these measures—particularly when pay is linked to performance—can inadvertently penalise providers who care for those most in need, creating perverse incentives to exclude these patients. Risk adjustment models sometimes include socioeconomic status, but these can also mask real disparities in quality. An “equity blind” approach cannot account for the non-clinical factors that influence health outcomes, and it may stop us learning which components reduce disparities and which do not. Equity oriented performance measurement takes these factors into account, and it can make systems and providers publicly accountable for the communities they serve.

Indeed, performance measurement can be a blessing, not a curse, for efforts to reduce inequities in quality. With adequate data, we can routinely measure and monitor progress, learn what tools and interventions work, develop and test new interventions to eliminate disparities, and understand a dimension of quality that has thus far seemed intractable. Ultimately, equity in health outcomes will probably be achieved only if we target the barriers that stop the providers serving disadvantaged patients and communities from reaching their quality targets. To investigate and eliminate disparities, we need to stratify performance data by the patients’ sex, ethnic origin, and other socioeconomic variables. This will
allow us to build an evidence base for implementing change that will maximise benefits and minimise harms. Equity must become an integral component of performance measurement.


### Involving patients in the BMJ

**Another step towards achieving our goal of helping doctors make better decisions**

The BMJ is a journal for doctors. Its mission is to lead the debate on health and to engage, inform, and stimulate doctors, researchers, and other health professionals in ways that will improve outcomes for patients.

In recent years, patients and the public have become increasingly involved in shaping health care. In the UK, the government is promoting the inclusion of members of the public in strategic decisions about health services and policy at local and national level, and doctors are being encouraged to involve patients in treatment decisions. Most British medical royal colleges have established patient advisory groups and value those groups’ contributions to their work. Gradually, also, patients have been taking on more active teaching roles in medical training.

Recognising this trend, the BMJ established its own patient advisory group in 2002 chaired by Mary Baker, a member of the BMJ’s editorial advisory board and president of the European Parkinson’s Disease Association. The group’s role is to help the BMJ achieve its mission to help doctors make better decisions. It does this by suggesting new content and commenting on the journal’s existing content in ways that will educate readers about patients’ needs. It began with a core of members mainly from the United Kingdom and from a few specialist areas (including cancer, dermatology, general practice, and medicines management).

Our plan now is to extend the group geographically and across more fields of medicine, to create a virtual group of patient advisers who will join the growing network of BMJ editorial advisers around the world.

Since the patient advisory group was formed patients have contributed editorials, commentaries, personal views, articles, and letters on a range of subjects. Perhaps their most obvious contribution has been through our intermittent series of patient journey articles—17 to date—which aim to help readers understand how a patient feels when confronting a difficult diagnosis, living with a chronic condition, or going through a traumatic medical event.

Doctors can, of course, be patients, too. Indeed, several patient journey articles have been written by clinicians who are themselves patients or carers. Increasingly, patient journeys have been enhanced by the addition of commentaries from clinicians, which help identify and explain the lessons doctors can learn from them. We are always pleased to consider articles for this series.

Good writing is a hallmark of the BMJ, but people with interesting and worthwhile stories to tell should not be deterred from telling them just because they are not accomplished writers. The patient editor is always prepared to help authors, by advising on a manuscript’s potential and helping shape it to match the journal’s needs.

All this is just a starting point. We believe patients have far more to contribute to the BMJ than simply their own experiences of illness and treatment. Via the patient advisory group, we look forward to their input on matters as wide ranging as national health policy; the quality and direction of clinical research; healthcare inequalities; conundrums over the length and quality of life and quality of death; doctor-patient communication; the differences between treating disease and treating the patient; the respective values of anecdotal and research evidence; and the changing nature of society and its implications for health care.

The redesign of the online and print versions of the BMJ should facilitate greater patient involvement. We will explore ways of achieving this, always bearing in mind that doctors are our main audience and that the clinical relevance and scientific quality of the journal’s content are paramount. We hope that you will welcome the increasing involvement of patients in the BMJ and that whatever specialty you work in, it will help you make better decisions for your patients.
Mental health of applicants seems to be deteriorating

We are surveying the impact of Modernising Medical Careers (MMC) and the Medical Training Application Service (MTAS) on the mental wellbeing of junior doctors. The preliminary results from the 790 online anonymous responses to date are disturbing and require an urgent response.

Most worryingly, 165 (21%; 95% confidence interval 18% to 24%) respondents agreed or strongly agreed with the statement: “I have been having more thoughts of ending my life than usual”—an increased level of suicidal risk in an already vulnerable professional group. Most trainees (740, 94%) admitted to increased consumption of anxiety symptoms. Considerable numbers (402, 51%) also reported physical tearfulness (508, 64%), irritability (699, 67%), less enjoyment of sex (352, 45%), and agreed to experiencing anhedonia (526, 66%), appetite (330, 42%), and energy levels (571, 72%). A large proportion (66%) attributed it to financial problems.

Most trainees (740, 94%) admitted to the past six months, 759 (96%) attributing it to higher than usual stress levels over the future. Many (527, 67%) were aged 25-29. Respondents agreed or strongly agreed with the statement: “I have been having more thoughts of ending my life than usual”—an increased level of suicidal risk in an already vulnerable professional group.

Most worryingly, 165 (21%; 95% confidence interval 18% to 24%) respondents agreed or strongly agreed with the statement: “I have been having more thoughts of ending my life than usual”—an increased level of suicidal risk in an already vulnerable professional group. Most trainees (740, 94%) admitted to increased consumption of anxiety symptoms. Considerable numbers (402, 51%) also reported physical tearfulness (508, 64%), irritability (699, 67%), less enjoyment of sex (352, 45%), and agreed to experiencing anhedonia (526, 66%), appetite (330, 42%), and energy levels (571, 72%). A large proportion (66%) attributed it to financial problems.

Most worryingly, 165 (21%; 95% confidence interval 18% to 24%) respondents agreed or strongly agreed with the statement: “I have been having more thoughts of ending my life than usual”—an increased level of suicidal risk in an already vulnerable professional group. Most trainees (740, 94%) admitted to increased consumption of anxiety symptoms. Considerable numbers (402, 51%) also reported physical tearfulness (508, 64%), irritability (699, 67%), less enjoyment of sex (352, 45%), and agreed to experiencing anhedonia (526, 66%), appetite (330, 42%), and energy levels (571, 72%). A large proportion (66%) attributed it to financial problems.

Most worryingly, 165 (21%; 95% confidence interval 18% to 24%) respondents agreed or strongly agreed with the statement: “I have been having more thoughts of ending my life than usual”—an increased level of suicidal risk in an already vulnerable professional group. Most trainees (740, 94%) admitted to increased consumption of anxiety symptoms. Considerable numbers (402, 51%) also reported physical tearfulness (508, 64%), irritability (699, 67%), less enjoyment of sex (352, 45%), and agreed to experiencing anhedonia (526, 66%), appetite (330, 42%), and energy levels (571, 72%). A large proportion (66%) attributed it to financial problems.

Most worryingly, 165 (21%; 95% confidence interval 18% to 24%) respondents agreed or strongly agreed with the statement: “I have been having more thoughts of ending my life than usual”—an increased level of suicidal risk in an already vulnerable professional group. Most trainees (740, 94%) admitted to increased consumption of anxiety symptoms. Considerable numbers (402, 51%) also reported physical tearfulness (508, 64%), irritability (699, 67%), less enjoyment of sex (352, 45%), and agreed to experiencing anhedonia (526, 66%), appetite (330, 42%), and energy levels (571, 72%). A large proportion (66%) attributed it to financial problems.

Most worryingly, 165 (21%; 95% confidence interval 18% to 24%) respondents agreed or strongly agreed with the statement: “I have been having more thoughts of ending my life than usual”—an increased level of suicidal risk in an already vulnerable professional group. Most trainees (740, 94%) admitted to increased consumption of anxiety symptoms. Considerable numbers (402, 51%) also reported physical tearfulness (508, 64%), irritability (699, 67%), less enjoyment of sex (352, 45%), and agreed to experiencing anhedonia (526, 66%), appetite (330, 42%), and energy levels (571, 72%). A large proportion (66%) attributed it to financial problems.
is a viable alternative to conventional contrast angiography for assessing patients with peripheral arterial disease before treatment. The authors found an adverse event rate of up to 10% associated with contrast enhanced MRA, lower than other techniques and generally mild compared with conventional contrast angiography.

We draw attention to the association between the use of gadolinium based contrast agents for MRA and the development of nephrogenic systemic fibrosis, a newly described chronic, debilitating disease characterised by progressive fibrosis of the skin, heart, lungs, and pleura with considerable morbidity and mortality. Development is predominately restricted to patients with stage V chronic kidney disease (estimated glomerular filtration rate less than 15 ml/min) and in those with acute renal failure, especially with liver failure. Most cases have been associated with the use of gadodiamide (Omniscan), some with gadopentate dimeglumine (Magnevist), and a few with gadoversetamide (Optimark)—all linear gadolinium chelates.

We found nephrogenic systemic fibrosis in 3.1% of patients receiving renal replacement therapy in Glasgow exposed to gadodiamide—a similar finding to that of other groups—and a dose dependent relation.

Many patients with peripheral vascular disease will have concurrent kidney disease, and the small yet clinically significant risk of developing nephrogenic systemic fibrosis should be considered when deciding whether to proceed with contrast enhanced MRA in patients with advanced kidney disease.

Peter C Thomson, research fellow in nephrology, peter.thomson@northglasgow.scot.nhs.uk, Tara A Collidge, specialist registrar, Renal Unit, Glasgow Royal Infirmary, Glasgow G4 0SF, Patrick B Mark, specialist registrar, Jamie P Traynor, specialist registrar, Renal Unit, Western Infirmary, Glasgow G11 6PE

Competing interests: None declared.

5 Broome DR, Girguis MS, Baron PW, Cottrell AC, Kjellin I,


Further authors are: Keith Simpson, consultant nephrologist, Glasgow Royal Infirmary, Alan G Jardine, professor of nephrology, Western Infirmary, and Scott T Morris, consultant nephrologist, and Gales H Roditi, consultant radiologist, Glasgow Royal Infirmary.

WHAT ABOUT THE GPs?

We help treat acute coronary syndromes

I was disappointed that the role of primary care and cardiac rehabilitation in the long term treatment of patients with acute coronary syndromes was not acknowledged by Peters et al. A similar review in the Lancet made the same omission. The importance of cardiac rehabilitation after myocardial infarction has recently been emphasised by guidance from the National Institute for Health and Clinical Excellence. The evidence for the effectiveness of nurse led secondary prevention clinics for coronary heart disease in primary care has been included in the quality and outcomes framework of the new general practitioner contract. When such primary care based clinics are integrated with cardiac rehabilitation programmes, optimal longterm treatment is possible for patients with acute coronary syndromes.

Hasnain M Dalal, general practitioner, Truro TR1 2LZ, hmdalal@doctors.net.uk

Competing interests: None declared.


We’re still great for continuity

I was saddened, but not surprised, to see no mention of primary care in the editorial on transition of care in children with chronic disease. In the United Kingdom, young people with chronic diseases are likely to have a general practitioner. Over the course of their life that doctor will have received numerous letters about their care and plans. These can be, and should be, educational. When dedicated paediatric care is no longer needed, adult expert clinics are needed, but so are day to day care and acute management of disease complications. Although the current organisation, after the new contract, of general practitioner care is less easy to navigate for patients, there should be a familiar face of someone who knows this group of patients and their illness.

John Sharvill, family doctor, Deal, Kent CT14 7AU, john.sharvill@nhs.net

Competing interests: None declared.


NHS INDEPENDENCE

An NHS board is the way forward

The reports on removing the NHS from direct government control are heartening. There is, however, an option that gives the NHS its independence and removes the hegemony of one political party. Balancing political input into an NHS corporation that fully manages the NHS as described by Edwards will satisfy critics who complain that we can never remove politics from the NHS and that we need politicians to drive the change. The board should have MPs representing the main political parties, in addition to elected members from health professionals, trade unions, managers, and patient groups. One member one vote with two third majority decisions will ensure that no one party will ever again run the NHS with an eye on the next election—an electoral college as described by Edwards with one difference: members are democratically elected from their organisations rather than nominated by ministers.

Such a model would be ideal for Wales as it currently does not have foundation trusts or large scale privatisations. Since the May assembly election it has had a minority Labour government seeking coalition with the Liberal Democrats one day and Plaid Cymru the next, without yet settling on a solution—so, why not an all party NHS board?

Layla Jader, consultant in public health medicine, Welsh BMA Committee for Public Health Medicine and Community Health, Layla.Jader@nphs.wales.nhs.uk

Competing interests: None declared.

1 Hawkes N. Nuffield Trust backs independence for the NHS. BMJ 2007;334:1129. (2 June.)
4 Jader L. It is time to separate the NHS from direct government involvement. BMJ 2006;332:1518.
Doctors call for England’s CMO to resign

Zosia Kmietowicz TORQUAY

Doctors’ leaders have called for the resignation of the chief medical officer for England, Liam Donaldson, blaming him for a catalogue of disasters that is engulfing the NHS.

John Hyslop, chairman of the BMA’s Central Consultants and Specialists Committee, who proposed the motion at the BMA’s annual representatives’ meeting, cited as reasons for Professor Donaldson to resign the disagreement between doctors and the Department of Health over doctors’ regulation and the chaos created by the new system for allocating training places for junior doctors. Both were good ideas that had got “into problems because of mismanagement by the Department of Health,” he said.

Dr Hyslop also called the department’s proposal to lower the standard of proof needed to strike off a doctor—from the criminal one of “beyond all reasonable doubt” to the civil standard of “balance of probability”—as “rough justice for doctors and patients.”

“Deliver safe changes—something that is fit for purpose, not endless paper trails distracting us from caring for our patients,” he told the conference. “The nation is now threatened by the NHS in crisis.”

He said that in May 2006 the then chairman of the BMA’s council, James Johnson, and the chairwoman of the Junior Doctors Committee, Jo Hilborne, had been “knocking at the door” of the chief medical officer asking to discuss the medical training application system (MTAS), the new system for allocating junior doctor training posts, because they could foresee problems, but they were effectively frozen out.

Dr Hilborne said that Professor Donaldson had been “very distant” since MTAS ran into problems. “He has not been a very visible presence, and I feel he should have been watching it and stepping in when it went wrong,” she said.

NICE’s decision on drugs was “irrational”

Clare Dyer BMJ

The regulatory body that decides which treatments the NHS should pay for was accused of “irrational” decision making in the High Court this week for denying drugs to patients in the mild stage of Alzheimer’s disease.

The National Institute for Health and Clinical Excellence (NICE), which issues its guidance on the basis of cost benefit analyses, is facing its first legal challenge to a decision to restrict a drug’s availability on the NHS.

The unprecedented case was brought to the High Court in London this week by two drug companies and by the Alzheimer’s Society, representing patients and carers.

NICE’s guidance last year meant that nearly 100 000 patients a year in England, Wales, and Northern Ireland with mild Alzheimer’s disease were no longer entitled to certain drugs on the NHS. The drugs are the acetyl cholinesterase inhibitors donepezil (Aricept), rivastigmine (Exelon), and galantamine (Reminyl). Eisai, the Japanese manufacturer of donepezil, and Pfizer, which distributes it in Britain, asked the court to force NICE to reconsider its decision.

A key plank of NICE’s case was that its appraisal review application. It also says that when its appraisal committee first looked at acetyl cholinesterase inhibitors for “the whole cohort of mild to moderate AD [Alzheimer’s disease] sufferers, it did not even come close to achieving the levels of cost effectiveness generally required before NICE could recommend such use within the NHS.”

David Pannick QC, for Eisai, told Mrs Justice Dobbs that the drugs could “buy time and quality of life” for patients with mild symptoms.

The judge was expected to finish hearing the case this week, after the BMJ went to press, and to deliver judgment in July.
US health professionals demonstrate in support of *Sicko*

**Janice Hopkins Tanne** NEW YORK

Doctors, nurses, and health workers across the United States are demonstrating in support of *Sicko*, Michael Moore’s film attacking the US healthcare system. They are calling for a single payer system to replace the US private insurance programme, which leaves about 46 million people, or 16% of the population, uninsured. Health care is a hot issue in the coming presidential campaign.

The demonstrating health workers, calling themselves “Scrubs for Sicko” and wearing white coats or scrubs, handed out leaflets at the screenings of Moore’s film. The film, scheduled to open across the United States on 29 June, was shown in previews in Washington, DC, Chicago, and Manchester, New Hampshire, the state where the earliest primary elections to select candidates for party nominations for president occur.

The film opened early in one cinema in New York city last week. There, on a warm sunny afternoon on Broadway, nurses, doctors, medical students, and activists distributed information outside the cinema, posed for television cameras with their poster, “Health care is a human right,” gave radio interviews, and chanted “Hey, hey, ho, ho, insurance companies have got to go” and “Pills cost pennies, greed costs lives.”

They represented several groups: Physicians for a National Health Program, the New York City Central Labor Council, the Student National Medical Association, and the American Medical Students Association. Together, these and other supporting organisations represent more than 100,000 healthcare workers.

*Sicko* criticises the US health insurance lobby, which, it says, paid huge sums to the campaign funds of leading politicians—nearly $900,000 (£450,000; €670,000) to President Bush, for example—to support a bill requiring elderly Americans in the Medicare insurance plan to sign up to one of a confusing number of plans offering drug discounts (BMJ 2006;332:1352).

The bill, passed in the middle of the night nearly four years ago, prohibited Medicare from negotiating drug prices with manufacturers.

Tories want to set up a board to free NHS of political interference

**Michael Day** LONDON

The Conservative party plans to free the health service from political interference by handing over control of the day to day running of the NHS in England to an independent NHS board.

The radical plan appears in a white paper that will form the basis of the party’s health policy at the next general election.

Launching the document last week, the Tory leader David Cameron said that, in addition to the planned NHS board, a pledge to scrap national targets and devolve more power to doctors would further enhance the independence of the NHS.

The shadow health secretary, Andrew Lansley, said, “We need a service where the government and parliament set the framework, determine the overall resources, [and] agree the objectives and outcomes which need to be met, but don’t try to interfere in the day to day decisions about patient care.”

He said that the proposed NHS board would “represent patient and public interests.”

He added, “It will create powerful incentives for healthcare organisations—publicly owned and independent—to deliver greater quality and efficiency, which will benefit from a structure of independent regulation.”

Board members would be chosen by the health secretary and would be accountable to the Cabinet.

However, the Labour party’s chairwoman, Hazel Blears, said that the ‘Tories’ NHS board sounded like “a return to the days of nationalised industries.”

The Tories also pledged to put senior doctors in charge of local budgets, with power to decide how money is spent. Mr Lansley warned, however, that doctors who performed poorly in this role would have their salaries cut.

Hamish Meldrum, chairman of the BMAs General Practitioners Committee, said “We need to be cautious about the value of an independent NHS board” that family doctors “would have to be convinced of the need” for changes to the current system of performance related pay.

But many commentators remarked that, apart from the NHS board and the pledge to do away with national targets, the Labour and Tory health policies were similar.

Gill Morgan, chief executive of the NHS Confederation, which represents most NHS organisations, said: “We welcome the Conservative party’s commitment to the values of the NHS and a tax funded system. It is good news that that their proposals contain no violent change of direction or major reorganisation. We need a period of stability.”

Niall Dixon, chief executive of the healthcare think tank the King’s Fund, said that the Tories were “right to build on existing reforms” rather than attempt “a further potentially damaging reorganisation.”

However, he added: “We need to be cautious about the value of an independent NHS board. Handing power to such a board would not, by itself, guarantee local autonomy or a greater voice for patients.”

He also questioned the wisdom of scrapping targets.

*NHS Autonomy and Accountability: Proposals for Legislation* can be found at www.conservatives.com.
More recruitment from ethnic groups would improve NHS

Seye Abimbola BMJ

Recruiting more people from ethnic minority groups into the NHS in England would improve the care of patients, cut costs, and increase the skills of NHS staff, says a report by the government agency Race for Health.

The 64-page report sets out ways that trusts can increase the number of people from ethnic minorities that it employs, through pre-recruitment support, better information on access to jobs, and help for people who qualified overseas. The report says that recruiting people from ethnic minority groups for new specialist services that are aimed at those communities would improve health outcomes in those communities.

The report is based on a study of 15 primary care trusts in England that had each tried in various ways to increase employment of people from ethnic minority groups in their areas.

One of them, South Birmingham Primary Care Trust, set up a work experience programme and provided NHS placements to local teenagers from regeneration areas as a way to raise awareness of the NHS among ethnic minority communities.

Bristol Primary Care Trust used 30 volunteer mentors to help ethnic minority people at all skill levels to succeed in the NHS. Westminster Primary Care Trust helped hundreds of refugee doctors and dentists to meet UK registration requirements.

Helen Hally, national director of Race for Health—a programme sponsored by the Department of Health to find ways to improve health care in ethnic minority groups and to encourage recruitment of people from those communities into the NHS, said: “Our report shows that BME [black and minority ethnic] communities are still poorly represented within the NHS, particularly at the top.”

The report warns that without decisive action on NHS employment, disillusionment could set in among such communities, which by 2010 will provide half the growth in Britain’s working population.

Ethnic minority groups currently make up around 8% of the UK population. Although almost 14% of NHS staff come from an ethnic minority group, only three out of 400 directors of nursing are black, and just four chief executives in the NHS are black.

Inequality of access to health care is a major problem in the United Kingdom. About 40% of Bangladeshis and 60% of Pakistani children have visited a dentist, whereas the figure for all children in the UK is 90%.

Infant mortality in England and Wales among children whose mothers are from Pakistan is double the national average. Young black men are six times more likely than young white men to be sectioned for compulsory treatment under the Mental Health Act.

A Healthcare Commission study last year showed that most NHS trusts had not met the legal requirement to publish details on their websites of monitoring of employment by ethnicity.


Class action over Abbott’s pricing of drugs moves forward

Bob Roehr WASHINGTON, DC

A US judge has authorised a class action lawsuit against the drug company Abbott for its 400% hike in price, begun in late 2003, of the anti-HIV drug ritonavir (Norvir).

The lawsuit charges that the increase was a violation of US antitrust laws. It aims to roll back the increase and seeks compensation for everyone who has overpaid for the drug since the price increase.

Ritonavir had been developed as a protease inhibitor but did not work particularly well on its own. Over the course of using it with various combination treatments, clinicians observed a synergistic effect with other protease inhibitors. Ritonavir impeded the clearance of those drugs by the liver. Second generation protease inhibitors were developed that used ritonavir in subclinical doses as a “booster.”

When this role for ritonavir became apparent, Abbott increased the price of ritonavir by 400%, from $1.71 (£0.90; €1.30) to $8.57 per daily dose. The company said the rise reflected the increased “value” of the drug. It did not increase the price of Kaletra, its co-formulation of the protease inhibitor lopinavir with a booster of ritonavir.

The price increase sparked protests by numerous AIDS specialists and activists in the United States and abroad, but doctors often have little option but to continue to prescribe Ritonavir as part of their patients’ regimen.

The very early development of ritonavir had been undertaken with funding from the US National Institutes of Health (NIH), which granted patent use to Abbott. The outcry over the price increase prompted the NIH to launch a highly unusual investigation of whether Abbott’s price increase violated that patent.

The NIH ultimately found that it did not have the authority to revoke Abbott’s patent for ritonavir on the grounds of the price increase. In 2004 a class action lawsuit was launched on behalf of patients and healthcare payers who have suffered under Abbott’s alleged anti-competitive price increase.

Several rounds of pre-trial motions and appeals ensued.

On 11 June a ruling by the federal judge Claudia Wilken allowed the class action lawsuit to move forward to trial.
Routine HPV vaccine is recommended for 12 and 13 year old girls: The body that advises the UK government on vaccines has recommended that all girls aged 12 or 13 should routinely receive the human papillomavirus (HPV) vaccine. The Joint Committee for Vaccination and Immunisation says that the vaccine is beneficial. The Department of Health has agreed in principle and said that vaccination in England could begin in 2008.

Settlement is reached over claims of drug price fixing: Claims brought against a UK drug company for alleged anticompetitive conduct in connection with supplying generic drugs to the NHS have been dropped. A settlement was announced jointly by the Department of Health and the Goldshield Group, Goldshield Pharmaceuticals, and Forley Generics. Under the settlement, Goldshield agreed, without admitting liability, to pay the NHS £4m (£6m; $8m) and to cooperate in connection with the continuing civil claims regarding the alleged price fixing arrangements.

Number of tobacco related deaths in US falls by a fifth over 15 years: The number of deaths in the United States related to smoking fell by 19.9%, from 402 000 in 1987 to 322 000 in 2002, says research published in Nicotine and Tobacco Research (doi: 10.1080/14622200701397957). The study says that the number of Americans who smoke has fallen by 50% since 1965 but that the effect on mortality has received little attention.

European groups launch charter on heart disease: A “heart health charter” for Europe has been launched after agreement between 16 European health organisations and professional societies. The charter aims to reduce the burden of cardiovascular disease in the European Union and the WHO European region and reduce inequalities among countries in cardiac health. (For more information see www.heartcharter.eu.)

Children in England are buying and drinking less alcohol: The number of schoolchildren aged 14 years or over who buy and drink alcohol has dropped from 40% to 28% in the past two years, says a survey of 12 000 schoolchildren in northwestern England published by the Trading Standards Institute. But nearly a third (29%) who do drink are regular binge drinkers, consuming five or more units of alcohol at least once a week. The survey results can be seen at www.tsi.org.uk.

Aid workers are compromised by war on terror, UN official says

Peter Moszynski LONDON

Humanitarian workers are facing unprecedented danger because of the erosion of the concept of neutrality in the wake of the war in Iraq and the “war on terror,” said the former United Nations deputy general Mark Malloch Brown.

Giving the International Rescue Committee’s annual lecture at the Royal Geographical Society in London, Sir Mark said that “between 1997 and 2003 the number of relief workers lost annually had more than doubled to over 100.” Last year “60 aid workers were lost in Darfur alone.” This is partly because the number of aid workers has grown by 60% to 250,000, so “there are a lot more people to get in harm’s way.”

He said, “Most years we now lose more unarmed relief workers than military peace keepers. And more and more of them die as a consequence of political violence rather than, say, their Land Rovers tipping over.”

That the number of casualties wasn’t higher was only “because of ever more intense security measures, which have seriously impeded the international community’s ability to bring relief where it is needed,” Sir Mark said.

“Access to Somalia is on and off. Huge swathes of Darfur are at times closed to humanitarian access. There is almost no help at present to victims of war in Ethiopia’s Ogaden desert. Work in Iraq is almost closed off.

“The world is a much more dangerous place for those who cover conflicts”

Extensively drug resistant tuberculosis raises the possibility that tuberculosis that is susceptible to drug treatment will be replaced by a form with “severely restricted treatment options.”

WHO warns: “If this happens it would jeopardise the progress made in recent years to control TB globally and would also put at risk the plans to progress towards universal access to
Clinical trial results often overstate benefits of treatment

**Michael Day** LONDON

Failings in the way that clinical trials are designed and presented may lead doctors to overstate the benefit of treatments, experts warned last week.

The conference on clinical trials, organised by the James Lind Alliance and the *Lancet* and held at the Royal Society of Medicine in London, also heard that key groups of participants were often excluded from clinical studies and as a result were denied the benefits of evidence based medicine. Stephen Holgate, professor of immunopharmacology at Southampton University, said that children and elderly people were “especially neglected” in this area.

As another example he noted that the routine exclusion of smokers from asthma studies meant that it has only recently been discovered that inhaled steroids do not work in this group—decades after millions of smokers began taking these drugs for their asthma.

Professor Holgate said, “In order to redress the balance, more real world ‘effectiveness’ studies are needed, recruiting all comers and using more patient centred outcome measure and global assessments.” He added that such studies should cover a “wide range of age and ethnic groups to take account of adherence and cultural factors.”

More information is at www.lindalliance.org.

Social measures may control pandemic flu

**Richard Smith** BARCELONA

Non-pharmacological interventions may be as important as—or even more important than—drugs and vaccines in fighting pandemic flu, speakers at a conference in Barcelona said last week.

The international conference on health technology assessment heard from James LeDuc, a professor at the University of Texas who until recently helped to lead the US national strategy for responding to pandemic flu, how St Louis did much better than Philadelphia in the 1918 pandemic—long before effective drugs and vaccines were available. St Louis had its first cases on 5 October 1918, and on 7 October it took a range of measures, such as closing schools, theatres, and dance and pool halls and banning public gatherings, including funerals. In contrast, Philadelphia had its first cases on 17 September but didn’t act until 3 October, and on 28 September a city-wide parade was held. St Louis experienced fewer cases and a much slower increase in the number of cases. Comparisons of the spread of flu in other US cities in 1918 supported the case for “social distancing.”

Some scientists have proposed that a pandemic might be prevented by drug treatment on a “massive” scale when it becomes clear that the virus is beginning to spread among humans. Professor LeDuc was sceptical, however, pointing out that the success of such a strategy would depend on first class surveillance, international cooperation, adequate human resources and funding, and possibly a huge transfer of drugs from one country to another.

Social distancing will be important not just to help reduce numbers of cases but also to slow the spread of the epidemic, buying time for the production of a vaccine.

Clifford Goodman, a senior scientist with the Lewin Group, a healthcare consultancy firm that is based in Virginia, emphasised that the virus that eventually causes the pandemic may not be a variant of H5N1, as has been widely expected, but another strain altogether. He then spelt out the importance of drug resistance: by the time the pandemic arrives (and everybody thinks it inevitable) the virus may be resistant to the drugs now available.

RS chaired the conference’s session on pandemic flu, and his expenses were paid by the organisers of the conference.
Human rights groups plead for treatment for patients in Gaza

Merav Sarig [Jerusalem]
Human rights organisations in Israel are sounding the alarm about the difficult humanitarian situation in the Gaza Strip, which is endangering lives of people in hospitals.

They have called on the Israeli government to fulfil its obligations and open Gaza’s borders to the outside world and on the Palestinian factions to end killings near and inside hospitals in the area.

About 120 people have been killed and hundreds more injured as a result of the violent confrontations between the Hamas and Fatah factions in the Gaza Strip. Some of the fighting took place inside Gaza City and in the vicinity of hospitals.

Witnesses have said that some injured people coming for hospital treatment have been shot by Hamas militants inside hospitals.

A joint position paper issued by several of the humanitarian organisations states that the collapse of civil infrastructure as a result of the economic boycott and extended siege of the Palestinian Authority has made it impossible for rescue personnel to operate effectively.

Palestinian security forces have been accused of targeting hospitals, by shooting at patients entering hospitals or leaving.

The Palestinian Authority’s Ministry of Health says that more than 40 patients are in urgent need of medical treatment in Israel.

Government compromises on mental health bill

Clare Dyer [BMJ]
The UK government last week gave in to demands from critics of its mental health bill, agreeing to a compromise amendment that imposes new safeguards on powers to detain mentally ill patients.

The climbdown came over the most controversial clause in the bill, designed to permit patients with severe personality disorders to be detained if they are deemed to be a risk to themselves or others, even if they have committed no crime.

Ministers wanted to scrap the “treatability” provision in existing legislation, which allows patients to be detained only if their condition is considered treatable and if locking them up will help them. They wanted a looser power to detain if “appropriate medical treatment” was available, but they were defeated on the issue when the bill went to the House of Lords.

Last week the government accepted a compromise, proposed by the Labour backbencher Chris Bryant, that would permit enforced treatment if its purpose was “to alleviate, or prevent a worsening of, the disorder or one or more of its symptoms or manifestations.”

The amendment, backed by the mental health charity Mind and the Mental Health Coalition, went through without a vote, and the bill received its third reading in the House of Commons. It will now go back to the Lords, where the government could be forced to make further concessions.

Mr Bryant told MPs: “Any psychiatric unit cannot be prison by another name. It must be a therapeutic environment. Every person, whatever their mental condition—whether it is a mental condition which we presently believe is curable or not—must have the right to appropriate treatment.

“We simply cannot wash our hands of them. We cannot simply be detaining people for the purpose of detaining them. There has to be some kind of therapeutic benefit.”

Tim Loughton MP, for the Tories, welcomed the concession. “To remove the treatability requirement, whatever the government’s intention, is to permit indefinite preventative detention and to change the law from a health measure to one of social control.”
Public backs the idea of an independently run NHS

Zosia Kmietowicz TORQUAY

More than eight in 10 respondents to a survey on the NHS said that they would like to see doctors taking a lead role in deciding what is best for their patients and how money should be spent locally.

The survey, conducted by the BMA on the eve of its annual conference of representatives, also found that support among the public for an independent board of governors to run the NHS was widespread.

Sixty per cent of the 1000 respondents to the survey endorsed loosening the government’s control of the NHS, one of the proposals put forward by the BMA in its consultation paper on an alternative approach to health policy (BMJ 2007;334:969, 12 May).

Sam Everington, acting chairman of the BMA as the BMJ went to press (a new chairman was to have been voted in on Thursday), said, “The message that comes out of this [survey] is that the government really do need to listen to what patients and doctors are saying about the NHS. Patients want doctors to be involved in decisions about how local health services are run.

“The public and patients are united in their backing of an independent board to run the NHS, and we would urge Gordon Brown to make this a priority for when he becomes prime minister.”

The survey, which questioned people on the streets of Leeds, Dorset, London, and counties around London in June, found that 42% believe that the NHS has not got any better after 10 years of Labour health reforms. Only 34% of people believed that health policies introduced in the past decade have improved health services, while 24% thought that they had neither worsened nor improved.

Vivienne Nathanson, head of science and ethics at the BMA, said that the level of dissatisfaction with the NHS may be due to a mismatch between people’s expectations of what the NHS should provide and what services were offered.

She said, “The government has been telling patients they should be asking for certain services without asking doctors whether they can provide them.” She added that more research was needed to find out exactly what people meant when they said that the NHS was no better than it was 10 years ago.

Choice can worsen quality of care

Andrew Cole TORQUAY

There is no evidence that giving patients the ability to choose where they are treated improves the quality of care, a survey on the Department of Health’s own website showed.

An emphasis on choice could also increase inequality by favouring the more affluent and more articulate patients, BMA representatives heard at their annual meeting this week.

Terry John, from Waltham Forest, told the audience that the survey appeared on the website late last year but was removed just a few weeks later because, it was said, the views were not those of the department and the NHS logo had been used without permission.

Representatives agreed in a motion that the idea of patient choice does not offer real choices and insisted that the Department of Health work with the BMA and patients’ organisations to identify patients’ real needs.

Dr John said that the priorities for most patients were to be involved in decisions about their management, to be treated with dignity and respect, and to have their views listened to.

“We do this every day—that is where the real choice is going on,” he said.

He said it was paradoxical that patients had had no choice about the introduction of patient choice, and he added, “Isn’t it time they had one?”
It’s not what you say but how you say it

It is the job of the modern doctor to give patients the facts about a treatment, so they can make up their own minds about whether to accept it. But the facts—usually benefits and risks—can be framed in many different ways, and the method you choose could have a profound impact on the patient’s enthusiasm for treatment. In one study, people were most likely to accept preventive treatments when they were given the number needed to treat (the average number of patients who must be treated to prevent one event). They were significantly less keen when the same treatments were described in terms of their potential to postpone, not prevent, disease.

The researchers sent a questionnaire containing one of three scenarios to a sample of healthy Norwegians. In each case the facts were the same—taken from published trials of a statin to prevent heart attacks or a bisphosphonate to prevent hip fracture—but the researchers’ description of the facts was different. For both treatments, respondents “preferred” the number needed to treat option.

One explanation is that a number needed to treat sounds a bit like a gamble, say the authors. It implies that one lucky person will completely escape the feared outcome. People seem willing to bet that it will be them. 

*Ann Intern Med* 2007;146:848-56

Survival trends look worrying for women with diabetes

Between the early 1970s and the millennium, US men with diabetes enjoyed substantial improvements in mortality from cardiovascular and all causes that matched improvements in the non-diabetic population. Women with diabetes were left behind, however: an analysis of three nationally representative health surveys shows that their all cause and cardiovascular mortality remained essentially unchanged throughout the 30 years leading up to 2000. The excess annual mortality in women with diabetes compared with non-diabetic women more than doubled from 8.3 deaths per 1000 to 18.2. The study’s authors and a linked editorial agree that these trends look worrying for US women with diabetes. In the first survey, which covered the years 1971-86, women with diabetes had a clear survival advantage over men with the disease. This advantage was completely wiped out by the third survey (1988-2000). US citizens are now living longer thanks to better control of cardiovascular risk factors and better treatments for coronary heart disease, says the editorial. It seems likely that women with diabetes have missed out on both. Researchers need to find out why as a matter of urgency. They should also be looking closely at what has happened to women with diabetes since the millennium. 


Nephrology patients deserve better evidence

Observers estimate that about 19 million US adults have chronic kidney disease, roughly one in 10 of the adult population. Despite these huge numbers, there is a serious lack of good evidence to help inform their treatment, writes one leading nephrologist. Since 1966 fewer randomised trials have been published in nephrology than in any other branch of internal medicine. Not one good trial in the past 30 years has shown a clear mortality benefit for any treatment given to patients receiving dialysis. Long term survival hasn’t improved in recent years and may even be getting worse.

US guidelines for the treatment of chronic kidney disease rely heavily on evidence from observational and epidemiological studies, and tend to focus more on processes of care rather than outcomes that matter to patients and their relatives, he says. This has to change, starting with a close look at why the nephrology research community has failed to conduct much needed trials. Barriers must be broken down and targets for recruitment set to shake researchers out of their complacency.

Cardiovascular researchers could also help by including patients with chronic kidney disease in large prevention or intervention trials. All patients with kidney disease have a high risk of cardiovascular events, but so far they have been systematically excluded from most important cardiovascular trials. 

*JAMA* 2007;297:2630-3

Children with multiple sclerosis tend to get worse more slowly than adults who develop the disease, but they still reach a stage of irreversible disability on average 10 years younger than the adults, according to a recent European study.

The 394 patients who developed multiple sclerosis before the age of 16 took a median of 37 years to become permanently and severely disabled (unable to walk without support for more than 10 m), reaching this stage by a median age of 50. Compared with a further cohort of patients who developed the disease...
as adults, those diagnosed as children were more likely to be female, to have an exacerbating-remitting course of disease at onset (97.7% vs 84.3%, \( P=0.001 \)), and to have isolated lesions of the brainstem or optic nerve (16.8% vs 8.5% and 23.4% vs 17.9%, both \( P=0.001 \)).

In this study the patients with disease onset in childhood had a longer relapsing-remitting stage than those with disease onset in adulthood. The children converted to more persistent progression after a median of 28 years, at a median age of 41.

The authors hope their study will help to clarify the natural course of this neglected childhood disease. Over 2% of the patients seen in the participating French and Belgian centers developed multiple sclerosis as children.


### Alcohol is killing Russian working men

Russian men of working age have a poor life expectancy compared with men living in other industrialised countries. More than half die before they reach 65. Widespread alcoholism is at least partly to blame, say researchers, after their case-control study showed that 43% of deaths in men of working age were accounted for by hazardous drinking.

The study focused particularly on the dangers of drinking alcohol from cleaning fluids, medicinal compounds, and other “non-beverage” sources. All are duty free and up to six times cheaper than vodka. In the typical city in the Urals where the study was done, these alternative sources of ethanol were associated with odds ratios for death between 7.0 (95% CI 3.5 to 9.0) and 9.2 (7.2 to 11.7) compared with men who drank sensibly or not at all.

The researchers found a clear dose-response association between frequency of drinking non-beverage alcohols and death, which was largely independent of regular drinking. Men who drank non-beverage alcohol every day had 23 times the odds of death compared with men who drank non-beverage alcohol rarely or never (odds ratio 23.2, 9.3 to 57.8). Perfumes, medicinal potions, and cleaning fluids contain up to 97% ethanol by volume. A typical Russian vodka contains 43%.

**Lancet** 2007;369:2001-9

### Oestrogen only HRT prevents coronary artery calcification in younger women

Younger women who take oestrogens to relieve menopausal symptoms can be reassured that the treatment won’t increase their risk of heart disease, say researchers. In a large randomised study women aged between 50 and 59 who took oestrogen only hormone replacement therapy after a hysterectomy developed significantly less coronary artery calcification than similar women given a placebo. Both groups took their pills for a mean of 7.4 years.

Coronary artery calcification is a good marker for atherosclerosis and correlates well with the risk of coronary heart disease, says a linked editorial (pp 2639-41). The protective effects of oestrogens in younger menopausal women are consistent with much of the randomised and observational evidence so far, and indicate that such women with bad symptoms can probably stop worrying about the short term cardiovascular effects of hormone replacement therapy.

The new study was a spin-off from the Women’s Health Initiative oestrogen only trial. Researchers used computed tomography of the heart to examine 1064 of the younger women participants. Treatment with oestrogen reduced coronary artery calcification by at least 42% (\( P=0.03 \)).

These findings may be reassuring, but they don’t necessarily indicate that oestrogens prevent heart disease, says the editorial. Doctors shouldn’t be tempted to prescribe them for that purpose.


#### First patients have gene therapy for Parkinson’s disease

Twelve patients with severe Parkinson’s disease have safely completed the first attempt at gene therapy for this disease. A year after surgery, a preliminary study reports that none has had any serious treatment related side effects, and, on average, the patients’ motor symptoms have improved.

The gene therapy was aimed at the subthalamic nucleus, which is overactive in Parkinson’s disease. Surgeons injected into the nucleus a viral vector (adeno associated virus) carrying the gene coding for glutamic acid decarboxylase (GAD). This enzyme catalyses the production of the inhibitory neurotransmitter γ-aminobutyric acid. The researchers hoped that γ-aminobutyric acid would inhibit the overactive subthalamic nucleus, restore downstream neurological circuits to normal, and help restore motor function.

The researchers and the author of a linked editorial remain cautious but optimistic. This phase I trial was not designed to find out if the treatment worked, just that it could be safe. Further trials, in larger numbers of patients with a sham surgery control group, now seem justified, they say. Meanwhile, these researchers will be watching their patients closely for immunological side effects from the virus or the gene.

**Lancet** 2007;369:2097-105

---

**News**

**Guinea worm is a waterborne disease**

In 1986 an estimated 3.5 million people worldwide were infected with guinea worm. Twenty years later that figure has fallen to about 25,000, thanks to a global eradication campaign pioneered by former US president Jimmy Carter. Now in its final stages, the campaign has been successful without the help of a vaccine or even an effective treatment, writes one observer. It has relied instead on old fashioned public health measures executed by dedicated community volunteers. The whole campaign has cost a paltry $225m.

In 1986 an estimated 3.5 million people worldwide were infected with guinea worm. Twenty years later that figure has fallen to about 25,000, thanks to a global eradication campaign pioneered by former US president Jimmy Carter. Now in its final stages, the campaign has been successful without the help of a vaccine or even an effective treatment, writes one observer. It has relied instead on old fashioned public health measures executed by dedicated community volunteers. The whole campaign has cost a paltry $225m.

In 1986 an estimated 3.5 million people worldwide were infected with guinea worm. Twenty years later that figure has fallen to about 25,000, thanks to a global eradication campaign pioneered by former US president Jimmy Carter. Now in its final stages, the campaign has been successful without the help of a vaccine or even an effective treatment, writes one observer. It has relied instead on old fashioned public health measures executed by dedicated community volunteers. The whole campaign has cost a paltry $225m.
The AIDS pandemic is now more than 25 years old, and for most of its history, scientists have been searching for an effective vaccine against HIV. There have been many false dawns, dashed hopes, and disappointments along the way as evangelical rhetoric has eventually given way to a more pragmatic acceptance that a vaccine would be great, and may even be possible, but it won’t be on offer at a clinic near you any time soon. The most optimistic experts predict it will be at least another 10 years before any kind of vaccine is available; the most pessimistic say it could take 50. Even then, the first vaccines will probably be only partially effective. Why is such an important task taking so long?

The trouble with HIV
HIV is one of the most complex viruses ever identified, and it’s extremely good at evading any immune mediated strategy directed against it. HIV is already genetically diverse—there are currently nine genetic subtypes (or clades) of HIV-1, the most prevalent strain—and new forms are emerging all the time. HIV mutates rapidly so scientists are trying to hit a constantly moving target. Any successful vaccine must be effective against multiple subtypes and will need constant surveillance and modification to keep it ahead of the inevitable steady stream of new variants.

HIV has a full menu of other defences. Critical surface proteins that help HIV enter human cells are protected by a layer of sugary molecules called N-linked glycans and by the ability to change shape during the process of infection. It’s also a retrovirus, inserting its own genetic material into human cells quickly and efficiently. Once established, infection permanently weakens the body’s defences.

An HIV vaccine would have only a few days or weeks to prevent HIV from establishing a permanent foothold in the body. That’s asking a lot for any vaccine, but with HIV scientists are in uncharted waters. There are no existing vaccines against retrovirus infections in humans, and there are no cases of natural immunity to help guide vaccine development. So far, over 60 million people have been infected with HIV worldwide. Not one has managed to clear the virus completely, even after successful treatment with antiretroviral drugs. We don’t know what a successful immune response against HIV looks like. Scientists are still trying to characterise the elusive “immune correlates of protection”—the specific immune responses that a vaccine must stimulate to successfully prevent infection.

Traditional techniques don’t work
Vaccinologists’ traditional weapons seem useless against such challenges. Live attenuated (or inactivated) vaccines, which have been so successful in the past against smallpox, polio, and measles, are not an option against HIV because of the theoretical possibilities of infection or shedding of live virus.

Another traditional vaccine strategy—raising neutralising antibodies to disable the virus and prevent infection—has also run aground. Back in the mid-1980s scientists found and characterised one of the surface glycoproteins that helps HIV gain entry to human cells. The protein is called gp120, and later a genetically engineered version became the basis for the first vaccine to reach an advanced stage of human testing (AIDSVax, VaxGen).

Researchers thought the gp120 vaccine would induce neutralising antibodies that would bind the invading virus and stop HIV entering cells, protecting the vaccinated person from infection. But in seminal trials published in 2005 and 2006, the vaccine failed to protect either gay men or injecting drug users despite producing antibodies in 90% of those vaccinated. The antibodies simply weren’t versatile enough to cope with HIV’s genetic diversity.

Progress is further hampered by the lack of a reliable animal model to road test candidate vaccines. Monkeys with simian immunodeficiency virus (SIV) are the laboratory rats of HIV vaccine research, but important differences between monkeys with SIV and humans with HIV have misled researchers at least once. The gp120 vaccine worked well in chimpanzees. When it comes to testing HIV vaccines, only humans will do.

What are the options?
Although the failure of the gp120 vaccine was not an unexpected disappointment, researchers remain doggedly determined
to find new immunogens that work better (or even work at all). A vaccine that induces broadly neutralising antibodies is still the holy grail of HIV vaccine research, because scientists believe it is the only sure fire way of preventing HIV infection. “We know these kind of vaccines are the key to preventing HIV, and we also know they are achievable in the long run,” says Wayne Koff, senior vice president of research and development at the International AIDS Vaccine Initiative, “We’ve already isolated monoclonal antibodies with broadly neutralizing capabilities, and we’re expecting further real advances within the next few years.” But scientists like Dr Koff are still at the basic science stage of their research. They have had to go back to the laboratory to work backwards from these antibodies to find the immunogens that might stimulate their production. And it’s slow going. No clinical trials are on the horizon.

Researchers have turned instead to the cell mediated arm of the immune system, the T lymphocytes that can find and destroy cells infected with HIV. Even in natural infections this component of the immune system can control viral replication for at least a few years. A vaccine that stimulates T cells would not prevent infection in the traditional sense but might at least suppress the infection long enough to delay or prevent the onset of AIDS, reduce patients’ dependence on antiretroviral drugs, and help stop the virus spreading.

Experts agree that this kind of vaccine, even a partially effective one, is the best we can hope for in the medium term. “The idea of using vaccines to control rather than prevent an infection is not so outrageous,” says Andrew McMichael, director of the Weatherall Institute of Molecular Medicine at Oxford University and leading AIDS researcher. “Many of us are infected with Epstein-Barr virus, for example. But our immune system keeps the virus well under control so for most of us it’s harmless. If we could get to a situation with HIV that mimics that natural control of Epstein-Barr virus, that would be great.”

Two T cell vaccines are already being tested in placebo controlled trials. The biggest, a phase III trial based in Thailand, has already randomised over 16,000 uninfected volunteers. Half of them have been given a combined vaccine designed to induce both T cells and neutralising antibodies. Researchers hope the combined strategy, called “prime and boost,” will work better than either strategy alone. But this approach is controversial, according to Professor McMichael, partly because researchers are using the failed gp20 subunit vaccine as part of the package.

Perhaps more hopeful is a recombinant adenovirus vector vaccine that carries three harmless HIV genes into human cells. The genes produce foreign proteins that stimulate a cell mediated immune response. This vaccine, which is manufactured by Merck, is being tested in 6000 uninfected volunteers in two trials. “These trials are critical,” says Professor McMichael. “Any clear evidence of an effect would be enormously encouraging because it’s the first vaccine to test the concept of protective cell mediated immunity alone in humans. A similar vaccine worked well in monkeys, suppressing replication of simian immunodeficiency virus, so I’m hopeful.” Preliminary results are expected in the next two or three years.

At the very least, repeated disappointments and setbacks have taught this determined research community a valuable lesson in humility. The buzz surrounding the two leading candidate vaccines remains muted. They have learnt to expect less. “The history of vaccine research is defined by successes built on failures,” notes Dr Koff. “Just look at malaria. Developing vaccines has always been a slow iterative process. Learning what doesn’t work enables scientists to focus on what eventually does work.”

Dr Gary Nabel, director of the US National Institutes of Health’s Vaccine Research Center is equally cautious: “This is going to be a long road. I think that these initial studies will hopefully allow us to put a stake in the ground and say that it is possible to generate immunity and tell us what mechanisms may be most effective. And then it will be up to us to refine that going down the road. We need to dig in for the long haul.”

**Will a vaccine be worth the effort?**

The vaccine research community is in harmony over this question. “Vaccines would be the best way to control HIV,” says Professor McMichael. “Even a partially effective vaccine would be a start, something we can build on.” On the other side of the Atlantic, Anthony Fauci and Margaret Johnston from the US National Institute of Allergy and Infectious Diseases agree that a vaccine would be an “enormously valuable tool” in the worldwide effort to control a pandemic that still infects an estimated 14,000 people every day.

It’s hard to know with any certainty how a vaccine would change the pandemic’s trajectory. But the International AIDS Vaccine Initiative, a not for profit organisation devoted
to finding a vaccine, estimates that a vaccine licensed in 2015 could prevent between one tenth and one half of the projected 150 million new infections expected between 2015 and 2030. Without one, the number of new infections each year would increase from around 6 million today to around 10 million by 2030 (fig 1).10

A vaccine would have the biggest effect in low and middle income countries. But, no one still believes, if they ever did, that a vaccine alone will be enough. A partially effective vaccine could even accelerate the pandemic by taking the brakes off high risk behaviours. Existing control measures including education, condoms, clean needle exchanges, and widely available antiretroviral drugs will become more, not less, important should such a vaccine ever get a licence.3

The belief in an HIV vaccine is so powerful that the search is fast becoming a global research industry. The past decade has seen a bewildering proliferation of collaborations, consortiums, agencies, and organisations dedicated to the effort and now led by the Global HIV Vaccine Enterprise (box).11 Predictably, funding for research is failing to keep up with demand. The drugs industry is only just dipping its toe in the water. Most of the money spent to date has come from the public sector (with the US giving the lion’s share), with regular top ups from the Bill and Melinda Gates Foundation.12 The enterprise estimates that to fully implement its strategy will cost $1.2bn (£600m–£900m) a year.13 In 2006, the global spend outside the commercial sector totalled only $84m (fig 2).14

Professor McMichael thinks the enterprise is doing a great job of setting the research agenda and coordinating the worldwide effort to find a vaccine. “But we still need a bit of room at the edges for innovation and free thinking. A small part of the global funding should still go to individuals working outside the mainstream. One good idea may be all it takes.”

HIV vaccine research has come a long way since the wildly overoptimistic predictions made by desperate politicians in the mid-1980s. The world waited over a century for a vaccine against typhoid once the causative agent had been identified. Later, it took nearly half a century to develop vaccines against polio and measles.3 HIV has rewritten the rule book since then, and researchers have had to start once again from scratch.

“The search for an AIDS vaccine is a far greater challenge than sending a man to the moon,” wrote Mike Powell and Mitchell Warren, president and executive director of the AIDS Vaccine Advocacy Coalition in their 2006 report. “When it came down to the space race, we knew where we were; we knew where the moon was; and we knew, roughly, how to get there. It was, essentially, an engineering problem. When it comes to an AIDS vaccine, we don’t know where the moon is—yet. But that doesn’t stop us from aiming for the heavens.”15

Alison Tonks associate editor BMJ
atonks@bmj.com

Competing interests: None declared.

2 Day M. AIDS expert doubts vaccine will be found in near future. BMJ 2007;334:1133.
4 Gallo RC. The end or the beginning of the drive to an HIV preventive vaccine: a view from over 20 years. Lancet 2005;366:1894-8.
11 Global HIV Vaccine Enterprise. About the enterprise. www.hivvaccineenterprise.org/index.html

Key organisations in HIV vaccine research

- International AIDS Vaccine Initiative (www.iavi.org)
- AIDS Vaccine Advocacy Coalition (www.avac.org)
- Center for HIV/AIDS Vaccine Immunology (www.chavi.org)
- Joint United Nations Programme on HIV/AIDS (www.unaids.org)
- HIV Vaccine Trials Network (www.hvtn.org)
- Collaboration for AIDS Vaccine Discovery (www.cadvd.org)
- Vaccine Research Center at the National Institutes of Health (www.vrc.nih.gov/VRC)
- EuroVacc Foundation (www.eurovacc.org)
- Global HIV Vaccine Enterprise (www.hivvaccineenterprise.org)
BODY POLITIC Nigel Hawkes

Collision, collusion, and confusion

Can choice, localisation, and other NHS agendas all be followed successfully at the same time?

Choice is the mantra of the new NHS in England. Since the beginning of 2006 all patients across the country have theoretically been able to choose where and when they get hospital treatment—a great leap forward in empowerment of patients, if we are to believe ministerial statements on the subject. Hernias in Halifax, gall bladders in Gloucester: the world’s your lobster, my son, as Arthur Daley used to remark in Minder.

But it is never long in the NHS before one policy begins to collide with another. No sooner was choice up and running than ministers discovered the joys of localisation. Services offered locally, conveniently, and more cheaply formed the basis of Our Health, Our Care, Our Say, the white paper that also emerged in 2006.

GPs and independent companies are now being encouraged to provide such services in competition with hospital trusts. Primary care trusts are uneasy about this — and with good reason. Rightly or wrongly they still feel a responsibility for the preservation of secondary care; and an uncontrolled “free for all” could seriously disrupt the local NHS economy.

The lack of clear market rules is a major problem. Combined with practice based commissioning, the choice and localisation agendas have created conflicts of interest that are screaming out to be resolved. Services that are based in primary care occupy a favoured position. Under practice based commissioning, GPs both provide and commission these services, abolishing the purchaser-provider split that is the basis of the market—and then are free to refer their patients to them. Primary care services that aim at keeping people out of hospitals are also allowed to undercut the tariff, giving them a competitive advantage. The result is potentially unfair to hospitals and to the private providers that the government has encouraged to enter the market.

The aim of practice based commissioning was to counter the tendency of secondary care to soak up all the available resources by giving GPs an interest in keeping patients out of hospital. But it cannot, surely, have been intended, in the words of Simon Stevens in a recent issue of Health Service Journal, to be “an opportunity for GPs to form local cartels capable of channelling taxpayers’ cash to their own, for-profit, practices through the supply of substitute secondary care or diagnostic services, entirely immune from normal procurement rules or fair and transparent competition.”

Mr Stevens, of course, has interests of his own. A former health adviser to the prime minister, he now chairs UnitedHealth Europe, which itself is bidding for contracts to supply such services. However, he is not exaggerating. The healthcare think tank the King’s Fund made the same point in more moderate language in a recent report, calling for the Department of Health, “as a matter of some urgency,” to provide a clear set of rules for competition in health care.

Take choice, for example. It applies only to treatments “on the tariff,” the list of prices that hospitals are allowed to charge for each procedure. Hospitals are not allowed to charge less than the tariff, so giving a patient the choice between a range of hospitals is cost neutral for a primary care trust. But GPs’ services are not on the tariff. They are allowed to charge less. And because they are not on the tariff they are not formally part of choice. Patients can be encouraged to use such services without being offered choice at all—and, because these services are provided by GPs whom they trust, are likely to do so.

True, the national guidance Choice at Referral says that although many patients will be content to choose from local services, “GPs will be expected to tell patients that the new national menu also exists and to discuss clinically appropriate options available.” The General Medical Council says that there is a more general duty to inform patients if GPs have any financial interest in an organisation they plan to refer them to. What happens if they don’t? They are hardly going to be named and shamed, I suspect, or struck off or even rapped on the knuckles. How will anybody ever know?

The losers will be the acute trusts, who will find it increasingly hard to compete for patients against GPs with a special interest or GP funded diagnostic centres and the private companies hoping to get a foothold in the market. Few in the NHS would shed many tears for the private sector, but without its involvement the market simply won’t fly. The benefits of marketisation will be lost, and another reform will bite the dust without having even dented the tough carapace of the NHS. This may be just what many doctors and primary care trusts hope for, but it is not the government’s intention.

Quality is also an issue. GP provided services fall outside the remit of the Healthcare Commission, so nobody will know if they are as good as those delivered by acute trusts. The evidence so far is not especially encouraging.

Research carried out by Martin Roland and colleagues at the National Primary Care Research and Development Centre at Manchester University and commissioned by the health department found that GPs were good at delivering care for chronic conditions but less good at minor surgery, and that GPs with a special interest deliver more accessible care and shorter waiting times than hospital outpatient clinics. But the cost of services provided by GPs with a special interest is actually higher, and such services running without the support of local consultants may be unsafe.

The research concludes that moving secondary services or specialists to primary care settings does not reduce referrals and loses the economies of scale that hospitals provide. How odd it is that the health department didn’t issue a press release to alert us to this interesting study.

Nigel Hawkes is health editor, the Times. nigel.hawkes@thetimes.co.uk
RICHARD GRANGER’S LEGACY

Computer says yes—and no

What is the future of the NHS IT programme now that its supremo has quit? Michael Cross reports

The NHS’s IT programme —progress so far

- A central information “spine”—all NHS organisations are now connected to the spine, although its main function, to carry summary healthcare records, remains a “far-off dream”
- Electronic booking—the NHS has failed to meet targets for that proportion of bookings handled electronically, although the NHS’s outgoing IT programme director, Richard Granger, claims that IT is not to blame
- QMAS (quality management and analysis system)—national installation of software to support new GP contracts and payment by results
- PACS (picture archiving, communications, and storage)—Connecting for Health says that 75% of trusts in England are now using the technology
- Electronic prescribing—slow to roll out. Connecting for Health says that the service is being used for 11% of daily prescription messages (although in tandem with paper prescriptions)
- Electronic records in secondary care—the IT programme’s biggest failure. The original goal was NHS-wide availability by 2005. Of the two major suppliers, one has installed an “interim” system, while the other is only just rolling out systems

Five years ago, as the NHS considered the Wanless report’s call for increases in national spending on health, nearly everyone involved in trying to computerise health care agreed on two things: firstly, that information technology (IT) needed new investment, ringfenced so it could not be diverted to more urgent needs; secondly, that IT needed strong central leadership to coordinate developments and to ensure that money was wisely spent.

Remarkably, the government granted both wishes. The 2002 public spending round included £2.3bn (€3.4bn; $4.6bn) earmarked for healthcare IT in England. In June 2002 a Department of Health strategy announced that a “new national IT programme director” would be appointed to “improve the leadership and direction” given to IT and ensure “ruthless standardisation.” Five years on the 2002 consensus has evaporated. The constituency of individuals with opinions about IT in the NHS—vastly broader than in 2002—is divided over the technology, management, and ownership of electronic health information. The polarisation of debate, and the fact that it now involves clinicians, politicians, and civil liberties campaigners, as well as IT specialists, is a legacy of the man hired as IT programme director, Richard Granger.

Granger, who has announced that he plans to leave his post later this year (BMJ 2007;334:1290), was recruited in autumn 2002 after a career with management consultancies, where he specialised in installing IT for large companies and government departments. From the beginning he had a high personal profile, including the distinction of the highest salary on the civil service payroll. In 2004, when Tony Blair made a major speech on the future of the civil service, Granger was the only civil servant, apart from the cabinet secretary, mentioned by name. The announcement of his resignation—two weeks before Blair him-
The second flaw was a failure to engage properly with clinicians at the outset of the design of the electronic health record.

QMAS (the quality management and analysis system), hurriedly deployed in 2004 to support a new contract for GPs that involved payment by results. Another is picture archiving, communications, and storage (PACS) technology for handling digital x-ray pictures and other diagnostic images. Although a proved technology, PACS was at the bottom of priorities in the 1998 vision of electronic health records, largely because of cost. A national procurement in 2004 moved PACS up the agenda, and Connecting for Health says that three quarters of hospital trusts in England are now using the technology.

By contrast, electronic prescribing, seen in the 2002 plan as a “quick win,” has been slow to roll out, partly because of the difficulty of dealing with community pharmacies. Connecting for Health says its electronic prescribing service is now being used for 11% of daily prescription messages, but in almost all cases these run alongside paper prescriptions.

The programme’s biggest failure is over the installation of electronic patient records in secondary care. The 1998 strategy envisaged these being available across the NHS by 2005, procured trust by trust from at least a dozen suppliers. The national programme’s “ruthless standardisation” replaced this market with two key software firms, the UK firm iSoft and the US’s IDX, later replaced by Cerner. Both encountered problems developing systems to the specification required by the NHS; iSoft has relied on installing an “interim” system, while the roll-out of Cerner’s systems began late and is only now getting under way.

In retrospect, the national IT programme as executed by Granger contained two big mistakes. One was in the contract structure, which did not reflect NHS loyalties on the ground and alienated the existing IT community. The second flaw—which Granger vehemently denies—was a failure to engage properly with clinicians at the outset of the design of the electronic health record. Granger’s departure, and Gordon Brown’s arrival as prime minister, create the conditions for face saving changes of policy. Despite the knee-jerk political and media verdicts of failure, thanks to Granger the blocks of compatible technology are now becoming available to build the world’s largest and most integrated e-health service—if the will to do so is there.

Michael Cross is a freelance journalist, London
michaelcross@fastmail.fm

RESEARCH, p 1360, and VIEWS & REVIEWS, p 1373

What’s on bmj.com

Protecting vulnerable populations

A recent BMJ article on the treatment of mentally disordered offenders triggered a range of responses, writes Birte Twisselmann.

Becky Sales and Nigel Mackenzie propose that the new Mental Health Bill be amended and a time limit imposed for transfer of mentally ill offenders from prison to hospital to guarantee equivalence of care and basic human rights (BMJ 2007;334:1222). They also propose that the bill should contain statutory obligations to ensure that patients who are judged as needing hospital treatment while in police custody or in the court system cannot be sent to prison. Prison capacity is not great enough, and, at the same time, more prisoners are awaiting hospital beds.

Andrew Fraser, director of health and care in the Scottish Prison Service, and his colleagues point out that all mentally ill offenders in Scotland have to be transferred to hospital because of a lack of inpatient prison facilities. However, the prison population is bigger in England and the number of psychiatric beds is greater in Scotland, while the configuration of mental health services is different in the two countries. They add that adequate services, clear purpose, and good understanding between prisons and secure hospitals are needed.

Peter O’Loughlin, a drug and alcohol recovery specialist in Kent, agrees that mentally disordered offenders do not belong in prison. He reminds us, however, that they are in prison for the crimes they have committed. Should those crimes be ignored, or the offenders be found not guilty, for the sake of treating their disorder?

Ciaran Regan, psychiatric specialist registrar in Pentonville Prison in London, is concerned that the fact that mentally disordered prisoners are detained—but cannot be treated adequately in prison facilities—reinforces society’s view that detention is all that is needed for people with mental health disorders, thus emphasising the disparity between physical and mental health care. Labelling personality disorders as untreatable is questionable, adds Martin Zinkler, consultant psychiatrist in London, and can increase stigma and the feeling of hopelessness that surrounds many such patients.

Nisha Shah, locum consultant psychiatrist in London, suspects that imprisonment also reinforces negative attitudes towards offenders. Crucially, she blames political expediency for the lack of willingness to change legislation—because such a change may well not win votes.

Birte Twisselmann is assistant editor, bmj.com btwisselmann@bmj.com

The full text of these responses is available at www.bmj.com/cgi/eletters/334/7605/1222
Time to move towards opt-out testing for HIV in the UK

M Hamill and colleagues believe the UK could do more to ensure people know their HIV status

The diagnosis of HIV infection is the point of entry to prevention and treatment services. Yet many people are unaware that they are infected. The estimated proportion of people who remain undiagnosed ranges from 90% in sub-Saharan Africa, to one third in the United Kingdom, and a quarter in the United States. The Secretary General of the United Nations declared in 2006 that “Countries should promote, through global and national campaigns, the ideal that each person knows his or her HIV status and has access to AIDS information, counselling and related services, in a social and legal environment that is supportive and safe for confidential testing and voluntary disclosure of HIV status.” We consider how the UK should respond to this challenge.

Strategies for testing

HIV tests are usually done as part of diagnosis—in patients with signs or symptoms suggestive of HIV disease—or to screen for infection in people without symptoms. Most screening is done at the patient’s request or because a healthcare worker judges a patient to be at increased risk for HIV infection and seeks consent for testing.

One way to increase knowledge of HIV infection status is to use an opt-out approach to testing. This approach, which is also voluntary, considers HIV testing to be a standard part of medical care for particular patient populations. The populations are defined by variables that serve as surrogates for HIV prevalence or risk of HIV infection—for example, age, geographical area, country of origin, and healthcare setting. No judgment is made about an individual patient’s risk of infection. Patients are given information about HIV, how the test will be carried out, and are tested unless they specifically decline. Extensive pretest counselling is not required. Instead, counselling resources are focused on people found to be infected or on risk reduction strategies for those who test negative. Precedents of this model exist in several areas such as testing all NHS healthcare workers for hepatitis B virus.

New testing technologies make expanded testing easier. Point of care rapid tests can provide preliminary results during a single patient encounter. Rapid tests modified to use oral fluid samples obviate the need for either venepuncture or finger prick blood analysis.

In the US, the Centers for Disease Control and Prevention have revised their screening guidelines to make voluntary opt-out HIV testing a standard of care for people aged 13-64 years attending health care (box). The guidelines apply to all settings unless the prevalence of undiagnosed HIV infection is known to be <0.1%. The World Health Organization and the Joint UN Programme on HIV/AIDS recently published guidelines recommending provider initiated opt-out screening in concentrated and low level epidemics at sexually transmitted infection services, health services for populations at most risk, and antenatal, childbirth, and postpartum services.

The UK currently uses opt-out testing for patients attending genitourinary medicine clinics and for pregnant women attending antenatal care. The British HIV Association (BHIVA) states that, “a potentially important mechanism for limiting the HIV epidemic is the widespread use of HIV testing in a variety of clinical settings,” but provides no specific guidance on how the testing should be done. However, there is no recommendation for use of opt-out testing in other healthcare settings.

Case for routine opt-out testing

From 2003 to 2005, around 7500 people were newly diagnosed with HIV infection each year in the UK. The largest numbers of infections are reported to have been acquired heterosexually and, of these, most were acquired in Africa. Infections in men who have sex with men continue to rise. Additionally, about 20 000 UK residents aged 15-59 had undiagnosed HIV infection in 2005. Of those undiagnosed, almost half were men who had sex with men and about one quarter were men and women born in Africa.

These undiagnosed people risk progression to serious illness or even death. Furthermore, through unprotected sex, they may transmit their infection

HIV screening guidelines for the United States

- Opt-out HIV screening is recommended for patients in all healthcare settings
- People at high risk for HIV infection should be screened for HIV at least annually
- Separate written consent for HIV testing is not required; general consent for medical care should be considered sufficient to encompass consent for HIV testing
- Prevention counselling should not be required with HIV diagnostic testing or as part of HIV screening programmes in healthcare settings
to others, and mothers may transmit to their infants. Therefore earlier diagnosis has clear advantages for public and individual health. Once diagnosed with HIV infection, sexual risk behaviours of infected people have been shown to decrease substantially.\(^\text{10}\) The routine availability of highly active antiretroviral therapy adds weight to the argument for more extensive testing.

Routine opt-out testing, which makes no judgment about an individual’s risk, could also help reduce the stigma associated with testing. Stigma is an important barrier to HIV testing because infection is associated with sexual behaviour and drug use. When the infected person is homosexual or a member of an ethnic minority, the stigma may further increase.

Another consideration is the time taken up by increased HIV testing in general practice surgeries, accident and emergency departments, and hospital wards. The time needed for each patient is less for opt-out testing than for opt-in testing because extensive counselling and specific consent are not required.\(^\text{11}\) However, more patients will be tested. Programmes for routine screening have been instituted in emergency departments and urgent care centres at several US hospitals and yielded relatively high rates of previously undiagnosed HIV infection.\(^\text{12,13}\) Similar findings have been reported in a UK accident and emergency department.\(^\text{14}\)

Cost effectiveness of opt-out testing will vary according to several factors, including HIV prevalence in the population to be screened. Paltiel and colleagues recently showed that routine HIV testing using rapid tests would cost less than $50 000 (£25 000; €37 000) per quality adjusted life year (QALY) gained in US adults with a prevalence of undiagnosed HIV infection above 0.2%.\(^\text{15}\) No comparable cost effectiveness data are currently available for the UK.

Evidence of benefit
To inform a discussion of expanding opt-out HIV testing in the UK, we first need data on the likely yield from a changed testing policy. The best data come from unlinked anonymous prevalence surveys. Such surveys of men who have sex with men attending UK sentinel genitourinary clinics in 2005 showed the prevalence of previously undiagnosed HIV infection was 3.2%.\(^\text{2}\) Prevalence was highest in London (3.8%). Although people attending genitourinary medicine clinics presumably have a higher HIV seroprevalence than the rest of the population, these data suggest that screening in other facilities serving men who have sex with men would detect additional infected people.

As expected, unlinked anonymous surveys of childbearing women in the UK show much lower HIV prevalence, with undiagnosed infection detected in only 0.09% of women in England and Scotland.\(^\text{2}\) Again, infection rates were highest in London, especially in south east London, where the prevalence was 0.6%. Prevalence was highest in women from sub-Saharan Africa (2.4%) and from central America and the Caribbean (0.82%).

Further surveys are needed in areas of known increased HIV prevalence and in facilities that are known to serve people at increased risk of infection. Ideally, they should be based in facilities that already routinely collect blood samples for other purposes, such as accident and emergency departments and acute care hospital wards.

Since most people in the UK with heterosexually acquired HIV are from sub-Saharan Africa, testing Africans living in the UK would be likely to detect many previously undiagnosed infections. This strategy, however, raises ethical problems because some of this group may be illegal immigrants or failed asylum seekers and thus not entitled to free HIV treatment.\(^\text{16}\) Although these people may not get free antiretroviral drugs, knowledge of HIV status could reduce both horizontal and vertical transmission. Furthermore, they may be able to access affordable prophylaxis against opportunistic infections.

Any decision to expand screening also requires UK data on the cost effectiveness at various levels of seroprevalence. NICE guidelines suggest a threshold for cost effectiveness of between £20 000 and £30 000 per QALY gained.\(^\text{17}\) Given the mobility of populations, especially refugees, estimation of regional seroprevalence would need to be ongoing.

All public health decisions are based on weighing the pros and cons of a particular action or policy. In view of the clear advantages of early diagnosis of HIV infection for public and individual health, we believe the effectiveness and feasibility of expanded opt-out testing should be seriously assessed.

We thank Chris Conlon and Tony Randall for their helpful comments.
Routine testing to reduce late HIV diagnosis in France

Although around half the French population has had an HIV test, many people are still not diagnosed until the disease is advanced. Cyrille Delpierre and colleagues believe the answer is to expand routine testing.
detected.\textsuperscript{3} 4 Therefore, of the estimated 7000 people newly diagnosed with HIV in France in 2004,\textsuperscript{5} 3000 may have advanced disease.

**Consequences of late diagnosis**

Late diagnosis is associated with an increased risk of mortality. Sabin and colleagues found that one fifth of HIV related deaths occurred in patients who had discovered their infection within the six months before their death.\textsuperscript{6} Chadborn and colleagues also reported late diagnosis was a risk factor for short term mortality (odds ratio=10.76, 95% confidence interval 7.68 to 15.91).\textsuperscript{6} In France, mortality in the six months after detection of HIV infection was 16 times higher for patients diagnosed with advanced disease than for patients diagnosed earlier.\textsuperscript{7} The mortality two years after a first positive test result was 9% among those with advanced infection compared with 1% among those with earlier detection, and the difference in mortality remained four years after diagnosis. If we apply this rate to the estimated number who had infection detected late in France in 2004, 270 people will die in the subsequent two years, representing 16% of the 1700 HIV related deaths in France each year.\textsuperscript{8}

Late testing could also be important in the spread of the infection. In two trials to prevent transmission of HIV by increasing condom use,\textsuperscript{9} 10 transmission was reduced by 20% among patients with identified HIV infection. Knowledge of infection status could increase the use of preventive measures and will also reduce the risk of transmission by reducing infectivity through treatment to lower the viral load. Quinn and colleagues reported a fall in infectivity of 2.45 for each tenfold decrease in viral load.\textsuperscript{11}

Late diagnosis implies a long period without knowledge of infection and thus without access to care and counselling. Assuming that the normal CD4 cell count is \(900 \times 10^6/l\) and that this rate decreases by \(60-70 \times 10^6/l\) a year in infected people,\textsuperscript{12} 13 it takes about 10 years before the CD4 cell count falls below \(200 \times 10^6/l\). Infectivity could increase as the infection advanced. In a study of stable European couples, de Vincenzi and colleagues found that the cumulative incidence of seroconversion in the uninfected partner was 48.7% when the infected partner had advanced infection compared with 7.8% when the partner was in the non-advanced stage.\textsuperscript{14}

Estimating the number of infections caused by late diagnosis is difficult and open to criticism because of the lack of data and because it relies on assumptions about, for example, characteristics of the infection and infected persons, the period of infectivity, and the number of partners. However, we can assume that the probability of transmission by people with a late diagnosis is similar to that observed during the natural course of infection. A US study estimated that during the natural course of infection, HIV infected men who have sex with men would transmit the virus to 1.16 sexual partners over their lifetime and infected heterosexual men and women would transmit the virus to 0.43 and 0.14 partners respectively.\textsuperscript{15} Among people with a late diagnosis in our random sample of people diagnosed in France since 1996, 26.1% were men who have sex with men, 45.7% were heterosexual men, and 28.2% were women.\textsuperscript{5} Applying the US transmission rate\textsuperscript{14} and our sample composition to the 3000 people estimated to have been diagnosed late in France in 2004, men who have sex with men would have infected 908 people, heterosexual men 589 people, and women 118.

Late diagnosis may also increase the costs of hospital care and management of opportunistic infections, especially immediately after diagnosis. A study by Krentz and colleagues in Canada found that the direct costs of management were twice as high for patients who had CD4 cell counts \(<200 \times 10^6/l\) at HIV diagnosis than for those with a higher CD4 count.\textsuperscript{16} Similarly, in France the total mean monthly cost for the management of patients without AIDS was €670 (£450; $900) per person when the CD4 cell count was \(>500 \times 10^6/l\) compared with €1760 per person when the CD4 cell count was \(<50 \times 10^6/l\).\textsuperscript{17} During the month after the onset of AIDS, the cost increased from €1760 to €4530 depending on the opportunistic infections.

**Strategies to reduce late diagnosis**

HIV testing is more common in women and in people identified at higher risk of infection, such as men who have sex with men, young people, and those with multiple sexual partners.\textsuperscript{1, 2} Conversely, those who are detected late tend to be older, mainly men, heterosexual, and have stable partners and children,\textsuperscript{3, 4} populations that are not a priority target for testing. Thus the current policy results in people at low risk of HIV infection being at high risk of late detection.

With high quality HIV tests that limit false positive results, routine non-mandatory HIV testing of the
The rate of HIV testing in France is among the highest in Europe. Nevertheless, 40% of newly identified HIV infections are in people with low CD4 counts or AIDS. Current testing policy fails to reach the heterosexual population. People at low risk of HIV infection are thus at high risk of late diagnosis. Routine voluntary HIV testing should be implemented in primary healthcare settings.

SUMMARY POINTS

- Future infections will be diagnosed late if testing policy does not change. France therefore needs urgently to improve testing policy to include the heterosexual population at low risk of infection but at high risk of late diagnosis.

- Contributors and sources: CD has studied determinants of late testing in HIV infection. LC has published articles on the improvement of care management of HIV infected patients. FL has a long research interest in HIV testing policy and risk reduction. This article arose from previous works and Medline search. All the authors contributed to the literature review and to writing the paper.

- Competing interests: None declared.

- Provenance and peer review: Not commissioned, externally peer reviewed.

- Accepted: 4 April 2007


- Sidaction. Le sida en France. www.sidaction.org/infomer/sidafrenc


- Marks G, Crapeau N, Janssen R. Estimating sexual transmission of HIV from persons aware and unaware that they are infected with the virus in the USA. AIDS 2006;20:1447-50.
Impact of financial incentives on clinical autonomy and internal motivation in primary care: ethnographic study

Ruth McDonald, research fellow,1 Stephen Harrison, professor,1 Kath Checkland, research fellow,1 Stephen M Campbell, research fellow,1 Martin Roland director1

ABSTRACT
Objective To explore the impact of financial incentives for quality of care on practice organisation, clinical autonomy, and internal motivation of doctors and nurses working in primary care.
Design Ethnographic case study.
Setting Two English general practices.
Participants 12 general practitioners, nine nurses, four healthcare assistants, and four administrative staff.
Main outcome measure Observation of practices over a five month period after the introduction of financial incentives for quality of care introduced in the 2004 general practitioner contract.
Results After the introduction of the quality and outcomes framework there was an increase in the use of templates to collect data on quality of care. New regimens of surveillance were adopted, with clinicians seen as “chasers” or the “chased,” depending on their individual responsibility for delivering quality targets. Attitudes towards the contract were largely positive, although discontent was higher in the practice with a more intensive surveillance regimen. Nurses expressed more concern than doctors about changes to their clinical practice but also appreciated being given responsibility for delivering on targets in particular disease areas. Most doctors did not question the quality targets that existed at the time or the implications of the targets for their own clinical autonomy.
Conclusions Implementation of financial incentives for quality of care did not seem to have damaged the internal motivation of the general practitioners studied, although more concern was expressed by nurses.

INTRODUCTION
International interest in using financial incentives to improve quality of care is growing. A report from the US Institute of Medicine advises that “pay for performance should be introduced as a stimulus to foster comprehensive and system-wide improvements in the quality of healthcare.”1 In 2004 general practitioners in the United Kingdom were given substantial financial incentives to meet a range of clinical and organisational targets, known as the quality and outcomes framework.2 In the first year of these incentives high levels of achievement were reported3 and for some conditions a significant increase was shown in the rate at which quality of care was improving.4

Financial incentives may, however, have unpredicted effects.5,6 These include effects on motivation and morale. Many professional activities are intrinsically motivated—that is, they are carried out because the activity is inherently satisfying not because it carries an external reward, and there is evidence that internal motivation can be undermined by externally imposed incentives.7,8 This is potentially of great importance as intrinsic motivation has traditionally been regarded as a key attribute of high quality professional practice.9 We studied the effect of the financial incentives on practice organisation and the consequences for internal motivation in primary care clinicians. We particularly studied how practices organised themselves internally to achieve high contract scores, as surveillance and checking mechanisms in practices could potentially undermine motivation by producing internal conflict within primary care teams.9

PARTICIPANTS AND METHODS
We approached four practices in deprived parts of the north west of England to participate in our study. Two agreed to take part: one had a registered list of 12 000 patients and the other 8000 patients. Both had longstanding local reputations for providing high quality care and achieved high scores in the first year of the quality incentive scheme. We had no prior hypotheses that might inform a sampling strategy and since gaining access was the most important criterion these practices were chosen because they agreed to grant us access.

The research was aimed at exploring individual and group attitudes and patterns of behaviour. We therefore used observation of staff within their milieu, together with interviews and some analysis of documentation (for example, clinical incident reports, letters of complaint, job descriptions). We observed the clinics, general practitioner and nurse consultations, working patterns in the office and reception area, and practice meetings. We also carried out informal conversations and interviews with staff in the reception area and in the kitchen where they eat lunch, take breaks, and prepare drinks. We collected data from November 2005 to May 2006. This period of five
months (allowing for holidays) enabled us to examine
the impact of the contract in the run-up to the end of the
target year (end of March 2006) and the immediate
aftermath, including preparations for the new contract
indicators introduced from April 2006.

As we aimed to explore the workings of the practice
in the context of the new general practitioner contract
we made no prior assumptions about relevant and non-
relevant activities so that data collection was relatively
open ended. Data were collected by two of the
researchers, neither of whom had connections with
the practices: one is a general practitioner (KC) and
the other (RM) an ethnographer. These levels of
experience in general practice allowed the ethnogra-
pher to ask naïve questions whereas the other research-
er’s years of socialisation in similar settings proved a
useful source of information. Also the longitudinal na-	ure of the study was intended to reduce the problem of
“reactivity”—the extent to which participants modify
behaviour as a result of a heightened awareness of the
observer. We used contemporaneous notes of pro-
ceedings at meetings for the construction of detailed
notes. For conversations held in corridors, or other
informal exchanges, and for one meeting held in a gen-
eral practitioner’s home, where note taking was
impractical or would have inhibited candour, we
made notes as soon as possible afterwards.

We carried out formal interviews with all but one of
the doctors (12 general practitioners, two of whom
were salaried), all nurses (nine), all healthcare assistants
(four), and one practice manager and one senior recep-
tionist in each practice. Participants were asked to
describe their role and to comment on the new contract
and its impact on their work.

Much of the data included here relates to interviews.
However, observations and immersion in the practice
informed the content of the interviews and enabled us
to compare accounts with observed behaviours and to
place accounts within context. It may also be that staff
were less guarded in responses to interview questions
because they were aware that the researchers had spent
several months observing events and had a more
rounded view of the practice than would otherwise
have been the case.

From our observations we became aware of prob-
lems often not raised spontaneously in interviews,
such as the tensions caused by the perception of free
riding in one practice and the top-down surveillance
processes in both practices. We were also able to
draw on observational data to explore areas where
informal accounts diverged from our observations.
For example, we learnt that a general practitioner
who had expressed his support for computerisation
and the changes to working practices after the intro-
duction of the quality and outcomes framework was
actively resisting some of these practices in the consul-
tation. This enabled us to examine the apparent contra-
diction in a taped interview during which this doctor
admitted some degree of disaffection with and resis-
tance to revised ways of working.

Two researchers (KC and RM) independently coded
transcribed interviews to identify emerging themes.
Analytical themes and observational notes were dis-
cussed with members of the research team at regular
meetings throughout the study to test assumptions and
to identify areas for further investigation. Because of
possible differences in responses between profit shar-
ing partners and salaried general practitioners (who
might not participate in the financial rewards), we iden-
tify salaried doctors separately in the transcriptions.

RESULTS

Three major themes emerged from the analysis of tran-
scriptions of staff observed and interviewed in two
practices over five months after the introduction of
the quality and outcomes framework: the alignment
of financial incentives with professional values;
concerns about changes to clinical practice; and the impact
of surveillance within practices.

Alignment of financial incentives with professional values
Support for the financial incentive scheme was broad.
Doctors and nurses generally reported that the quality
and outcomes framework helped them provide what
they regarded as high quality clinical care (box 1).

Concern about changes to clinical practice
Some concern was expressed that care might suffer
from the introduction of targets that required

Box 1 | Alignment of financial incentives with
professional values

“I think because it largely focuses on things which we
should be doing anyway, it’s just an additional
motivation to make sure that we are practising good
practice . . . overall it’s good, and I think the fact that the
QOF (quality and outcomes framework) is changing and
we’re getting new targets I think that’s really important,
so I’m quite positive about it really” (practice A, salaried
general practitioner 9)

“But without a doubt, most GPs are now motivated to
perform well on certain quality issues, particularly
around secondary prevention. And I think that’s a great
thing. I mean it wasn’t there before—there wasn’t any
quality, it was all about quantity. The more you saw and
the more services you did to people, the more money
you got. So I think it’s very good really” (practice A,
general practitioner partner 12)

“I enjoy being given the autonomy to manage the
different diseases and manage my caseload. But also
it’s not just targets. The patient care has definitely
improved because we’ve been doing that, and so I think
some people believe we’re just number-crunching, but I
do think we are in this practice, I think because we
are actually meeting targets the patients’ care is
benefiting” (practice A, nurse 2)

“I mean certainly it’s definitely an improvement on the
previous system of payment . . . I think it is much more
now in line with good medical practice and you get
rewarded for that” (practice A, general practitioner
partner 10)
respondents to do things that they did not regard as routine good clinical practice:

[About giving standardised questionnaires to patients with depression] “Does it help me with the depressed patient? I don’t think it does. I think I was asking the questions anyway and I think doing the questionnaire actually detracts from the quality of the consultation” (practice B, general practitioner partner 1).

Despite overall support for the incentives, doctors and nurses in both practices described examples where the need to collect information affected the quality of individual consultations, with concern that the targets led to patients being treated “as a condition and not as the person that they really are:

“I think there’s just more onus on gathering information sometimes rather than seeing to the patient and caring for the patient and at the end of the day if a 92 year old lady is hypertensive and not on a statin . . . you get a bit frustrated with the QOF targets because they treat a person as a condition and not as the person that they really are, losing the individuality . . . That’s the problem I have. If it’s actually not pertinent to the person sitting in front of you, what am I asking it for? That becomes number crunching, it becomes ticking boxes, and that’s the bit that I don’t like. I think that frequently, that is the bit that is actually left to the nurses” (practice B, nurse 3).

This view was particularly prevalent among nurses, who were aware that much of the box ticking had been delegated to them. Templates in the electronic medical records were valued by staff as reminders of what to do but were considered as particularly constraining by nurses, who had less discretion than the doctors over their use. Some general practitioners were quite explicit that the process of following protocols was delegated to nurses, one doctor commenting that protocols didn’t “float my boat” (box 2). However, this doctor was initially reluctant to voice criticism and did so only after we observed him avoiding completing templates in consultations. Although critical of the processes involved (“I hate it”), this doctor also expressed general support for the aims of the quality and outcomes framework. Some respondents described potential distortions of clinical practice through neglect of non-incentivised aspects of care, although they described these as occurring in other practices rather than their own:

“There are other practices who are even more organised than us, in terms of getting the QOF points, but slightly miss out the cultural attitudes towards the patients . . . they bish-bang whallop through the scoring” (practice A, general practitioner partner 16) “Some practices say ‘we won’t do that because it’s not a QOF thing, we’re not going to look at it.’ We’ve not found the QOF has restricted us because we’re not here just to jump through those hoops. We’re here to do the best care we can” (practice B, partner 3)

**Box 2 | Concern about changes to clinical practice**

“I thought that you were supposed to tailor this care to every individual patient and meet patient needs . . . I think it takes away patient centred care really . . . I don’t think people appreciate being phoned up all the time and reminding them to come in and things . . . rightly or wrongly [this GP] strives for perfection and I think sometimes you have to acknowledge that you don’t get perfection all the time and whenever you’re dealing with patients and people you’ll never get perfection anyway” (practice B, nurse 1)

“When you are filling a template in, you do feel a little bit like, you know, you’re still listening to, you know, you are listening but you do feel a bit drawn away” (practice A, nurse 2)

“I never do [use templates] . . . I’m terrible. I mean our nurses are great at ticking boxes and using templates. They’re really good at that and they love some structure . . . I actually find it quite depressing to think about really — it just doesn’t float my boat . . . although I hate it, I do, you know, its very paradoxical but I actually think it’s a good idea and I think it makes things tangible and em quantifies things” (practice B, general practitioner partner 4)

**Surveillance of colleagues within practices**

The practices had different approaches to monitoring clinicians’ performance. In the larger practice individual staff were identified to lead on each area of the quality and outcomes framework, so that five nurses and three general practitioners had lead responsibility for one or more target areas. Each lead was free to decide how to organise the effort to achieve high performance levels and accepted responsibility for delivering targets. For nurses this delegated responsibility generally acted as a source of motivation. Clinical leads communicated areas of underperformance directly to their colleagues:

“...I will go in and privately speak to them and explain why it’s important . . . I did do one area of naming and shaming . . . that did work quite well . . . it’s personal isn’t it that you don’t want to be seen as the GP who’s falling down in a particular area?” (practice A, salaried general practitioner 9)

This approach sometimes caused frustration however:

“They forget we’re actually nurses and we are seeing patients and that is our first priority. Then to be told ‘we’re one per cent down’ [on a target], and you’ve not stopped all day because you’ve had poorly patients . . . that did get quite frustrating” (practice A, nurse 1) [On staff response to reminders about targets] “Some don’t like it at all, and get quite miffed and don’t talk to you for a few days afterwards” (practice A, practice manager 17) “You find you’re almost being told off for not doing something . . . there is the potential and the reality of constantly being told off” (practice B, general practitioner partner 3)

General practitioners who were not clinical leads sometimes waited until they were found out, rather than proactively pursuing contract targets:
[After a general practitioner away day discussion on free riding] “I just got into a rut ‘I suppose and I was, you know, very comfortable just seeing patients and doing nothing or very little else but I feel I’ve got a responsibility and I feel an obligation to maybe earn share myself more and be of more value in the practice” (practice A, general practitioner 10)

The implementation of the quality and outcomes framework was not initially perceived as controlling by these general practitioners, who were, by and large, content to let others take responsibility and to respond to prompts from colleagues:

“I think [QOFs] a fantastic idea really. And I love it frankly. Because in my old practice, I just had responsibility for everything . . . and so much more fell on my shoulders. If I was there now, I would be monitoring all this stuff. I’d be here in the evenings and the weekends, adding up numbers, as I know many GPs do. But here I just wait till someone says you know ‘we’re low on this target—pull your finger out.’ ‘Okay.’ And I love that. I think that’s how it should be” (practice A, general practitioner partner 12).

The small number of general practitioners who did complain about surveillance by colleagues also qualified this by expressing support for the quality and outcomes framework. Among general practitioners with direct responsibility for targets there was discontent at doctors perceived as “free riders.” As a result new written policies were developed in the practice to guide general practitioners’ behaviour. The timing of our study did not enable us to follow up the impact of this change in policy.

The smaller practice had a different style of implementation. The senior partner was a vigorous enthusiast for quality and outcomes framework targets, at times proposing clinical targets that were more stringent than those set out:

“Percentages are for wimps. I don’t accept that once you’ve hit 90% or 70% that’s OK. It’s not OK. It means that 10% haven’t been caught . . . We developed this zero tolerance to blood pressures a while ago. No one is allowed to say ‘it’s a little bit up leave it.’ It’s not acceptable. If you’re not doing something about it, [you need to] be able to justify why you’re not” (practice B, general practitioner partner 1).

This general practitioner monitored how other staff performed in their clinical work and acted on the findings on a day to day basis. As a result some of the staff felt that they were under constant surveillance. Despite this level of scrutiny, doctors and nurses in this practice still generally voiced positive attitudes to the quality and outcomes framework, although compared with the other practice overall critical comments were more common among nurses and those general practitioners who were “chased up.”

**DISCUSSION**

In the United Kingdom the introduction of the quality and outcomes framework was broadly welcomed by doctors and nurses as providing incentives to provide high quality care. Our study found that implementation of the incentives scheme did not seem to have damaged the internal motivation of the general practitioners studied, although more concern was expressed by nurses.

**Limitations of the study**

The study has several limitations. The practices were a small convenience sample and do not provide representative views of those working in general practice. Moreover, motivation cannot be observed directly but must be inferred from the behaviour or reports of participants. The research also describes only the early stages of a process that is evolving and further research is needed to examine the longer term impact of the incentives. Concerns about observer bias may arise in a context where one of the authors (MR) was among a small group of academics that helped to develop the original quality and outcomes framework in 2002. Data collection was, however, carried out by researchers who had no involvement in this development, whereas interpretation of the data evolved during discussions among a research team whose normative views towards the quality and outcomes framework were broad, from largely supportive to sceptical. This range of opinion meant that emerging interpretations were subject to ongoing scrutiny and challenge, which is likely to have reduced the extent of bias. The strength of the study design lies in the in-depth ethnographic approach to examine some fundamental underlying changes that may be taking place in practice. The generalisability of the results arises not from representativeness of the sample but from concepts that are likely to be relevant in other settings.

**Changes in practice organisation**

Our previous research predicted that financial incentives to improve quality of care will result in major internal reorganisation of practice, and we found this in both practices we studied. The most obvious change was the increased use of templates in electronic medical records to collect data on quality of care. Work from our centre has previously suggested that general practice risks becoming reduced to a set of biomedical tasks and that the imposition of external guidelines will result in a “Fordist” or production line approach to clinical practice. The nurses in our study were more sensitive to this matter than the general practitioners. The general practitioners maintained their claim to providing broader, less mechanistic care by explicitly or implicitly describing much of the work related to completion of clinical templates as a job for nurses.

In both practices the new contract led to increased surveillance of the clinicians. We have previously described the emergence of a new type of medical manager (restratification) at primary care trust level. In the present study we describe new regimes of surveillance emerging within practices in response to the quality incentives. The clinician-patient interaction, traditionally beyond the observation of the outsider, has been opened up to scrutiny.
WHAT IS ALREADY KNOWN ON THIS TOPIC

Financial incentives are believed to have improved the quality of chronic disease management in UK primary care.

The incentives may, however, have unintended consequences, such as threats to professionalism and internal motivation.

WHAT THIS STUDY ADDS

Doctors generally supported the quality and outcomes framework but were more negative about indicators that went beyond standard clinical practice.

New regimens of surveillance developed in practices, and this was perceived as a threat to internal motivation, especially among nurses.

Alignment of external incentives with professional values

In a previous study we argued that participation by English general practitioners in a quality improvement scheme, to their apparent financial disadvantage, could be explained by the coherence of internal and external goals. In general the respondents in the present study thought that the quality indicators in the quality and outcomes framework acted as an incentive to provide what clinicians themselves regarded as good clinical care. Despite tensions we found little evidence that the quality and outcomes framework was a threat to the internal motivation or core values of the general practitioners or evidence of crowding out of internal motivation that may result from imposed external incentives.

Greater concern was expressed about new quality indicators that had not previously been part of routine practice (for example, use of questionnaires for patients with depression and management of chronic renal disease). Nurses reported more conflict arising from the new style of work: some were positive about the quality and outcomes framework but others reflected views similar to another study, where nurses reported that the new contact had damaged nurse-patient relationships and decreased job satisfaction.

Conclusion

The United Kingdom, as with other countries, has introduced a series of measures in recent years to improve quality of care. Quantitative studies suggest that these changes have produced significant improvements in some aspects of care. Although adverse impacts on motivation are a potential drawback of financial incentives, all participants in our study expressed support for the quality and outcomes framework. This may in part be because, firstly, quality related incentives examined in this study build incrementally on the more modest incentives for particular procedures offered by earlier general practitioner contracts and are therefore already part of the social context of primary care. Secondly, participants generally equated pursuit of points on the quality and outcomes framework with quality of care, allowing them to perceive the incentives as aligned with pre-existing professional values. Thirdly, the general practice organisational and information technology changes that we have described embed the pursuit of points on the quality and outcomes framework into the everyday routines of general practices, thereby helping them to become features of primary care work that are taken for granted. Indeed, ambivalence and reluctant criticism in a small number of our study doctors may be indicative of the extent to which high performance on quality and outcomes framework targets is becoming accepted by doctors as synonymous with the delivery of high quality care. In such circumstances general practitioners may be reluctant to express dissent that renders them out of step with colleagues in their practice and wider. However, it is also possible that criticism voiced by a small number of doctors in this study relates not to incentives as such but to the manner in which they were implemented. The organisational changes associated with the implementation of the quality and outcomes framework in our study setting have the potential to fundamentally change the way clinicians relate to one another, and the long term consequences of these changes are hard to predict.

We thank the participants for their cooperation.

Contributors: RMcD and KC carried out the fieldwork. RMcD, SH, KC, and SMC designed the study, undertook data analysis, and wrote the paper. MR contributed to the analysis and writing the paper. RM was principal investigator and is the guarantor.

Funding: This work was done at the National Primary Care Research and Development Centre, which receives funding from the Department of Health. The views expressed are those of the authors and not necessarily those of the Department of Health.

Competing interests: MR was one of a small group of academic advisers to the BMA and NHS Confederation negotiating teams, which developed the original quality and outcomes framework in 2002.

Ethical approval: South Cheshire local research ethics committee.


Accepted: 2 May 2007
Implementing the NHS information technology programme: qualitative study of progress in acute trusts

Jane Hendy, research fellow; Naomi Fulop, professor of health and health policy; Barnaby C Reeves, reader in epidemiology; Andrew Hutchings, lecturer; Simon Collin, research associate

ABSTRACT

Objectives To describe progress and perceived challenges in implementing the NHS information and technology (IT) programme in England.

Design Case studies and in-depth interviews, with themes identified using a framework developed from grounded theory. We interviewed personnel who had been interviewed 18 months earlier, or new personnel in the same posts.

Setting Four NHS acute hospital trusts in England.

Participants Senior trust managers and clinicians, including chief executives, directors of IT, medical directors, and directors of nursing.

Results Interviewees unreservedly supported the goals of the programme but had several serious concerns. As before, implementation is hampered by local financial deficits, delays in implementing patient administration systems that are compliant with the programme, and poor communication between Connecting for Health (the agency responsible for the programme) and local managers. New issues were raised. Local managers cannot prioritise implementing the programme because of competing financial priorities and uncertainties about the programme. They perceive a growing risk to patients’ safety associated with delays and a loss of integration of components of the programme, and are discontented with Choose and Book (electronic booking for referrals from primary care).

Conclusions We recommend that the programme sets realistic timetables for individual trusts and advises managers about interim IT systems they have to purchase because of delays outside their control. Advice needs to be mindful of the need for trusts to ensure longer term compatibility with the programme and value for money. Trusts need assistance in prioritising modernisation of IT by, for example, including implementation of the programme in the performance management framework. Even with Connecting for Health adopting a different approach of setting central standards with local implementation, these issues will still need to be addressed. Lessons learnt in the NHS have wider relevance as healthcare systems, such as in France and Australia, look to realise the potential of large scale IT modernisation.
September and December 2004 and then again between January and April 2006. Stage 1 interviews concerned the implementation of the programme. Stage 2 interviews investigated how specific IT applications were experienced by staff and impacted on working practices (not reported here).

The data reported here are from the second phase of stage 1 interviews, with 25 senior NHS managers and clinicians in four acute trusts. To enhance generalisability, we selected four trusts that reflected a range of different organisational characteristics (table). We chose trusts that served both urban and more rural populations. The trusts differed in size, number of sites, performance indicators, financial situation, and the level of implementation of electronic functions. One site had a developed electronic system for patients’ records, another site had not implemented any electronic functions, while the remaining two sites had small pockets of implemented electronic functions. Participants included all local senior management staff involved in implementing the programme. At each trust these included the chief executive, director of information management and technology, medical director, and director of nursing, all of whom have responsibility for both fiscal and clinical probity.

In the 18 months since the first study, there have been several changes in personnel; of the 23 staff originally interviewed in 2004, only 11 were still in post in 2006 (two out of four chief executives, all four directors of nursing, two medical directors, and three directors of information technology). We analysed the views of the 11 staff interviewed in both phases of stage 1 separately from the views of the 14 staff interviewed only in the second phase to determine whether the views of the two groups of staff were substantially different.

An experienced qualitative researcher conducted semistructured interviews on a one to one basis at each trust. We developed the interview framework by drawing on literature concerned with the installation of computerised patients’ records to identify key constructs. Topics discussed included the processes and outcomes of implementing electronic health systems and the impact of Connecting for Health policies and communications. Interviews were taped and transcribed.

We analysed the data in three stages based on grounded theory principles of coding and theme abstraction rather than strict adherence to the theory of Glaser and Strauss. Literature on organisational change suggests the context and processes of change will be multilayered and complex. Using the comparative case studies we explored this complexity by examining variations within and between the trusts, taking account of organisational changes relating to NHS policy and communications.

We then grouped emerging themes according to the “context” (each trust’s characteristics) because “analysis of change needs to attend to the interplay between processes, people, and events both internal and external to the organisation.”

Building on our previous findings, we grouped themes around developing relations between each trust and other organisations involved in implementing the programme (including Connecting for Health and the local IT service providers). Two authors (JH and NF) independently read the interview transcripts and agreed key themes.

### Characteristics of trusts in 2003 that took part in survey of views on implementation of the new NHS IT system

<table>
<thead>
<tr>
<th>Trust</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Size</td>
<td>Large</td>
<td>Large</td>
<td>Large</td>
<td>Small</td>
</tr>
<tr>
<td>No of main sites</td>
<td>2 (earlier merger)</td>
<td>2 (earlier merger)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Financial situation*</td>
<td>Moderate deficit &lt;£5m</td>
<td>Small surplus</td>
<td>Large deficit &lt;£10m</td>
<td>Small deficit &lt;£1m</td>
</tr>
<tr>
<td>Performance indicators†</td>
<td>1 star</td>
<td>2 stars</td>
<td>0 star</td>
<td>2 stars</td>
</tr>
<tr>
<td>Electronic functions present</td>
<td>None at site 1; electronic orders at site 2</td>
<td>Electronic orders at both sites; PACs</td>
<td>None</td>
<td>PACS</td>
</tr>
<tr>
<td>Expected date for PAS replacement‡</td>
<td>Unknown</td>
<td>2007</td>
<td>2006</td>
<td>2004-5 ‘early adopter’ of electronic booking</td>
</tr>
</tbody>
</table>

PAS=patient administration system; PACS=picture archive and communication system.

*Annual accounts for 2002-3.
†Commission for Health Improvement (now called the Healthcare Commission) Clinical Governance Review 2002-3.
‡No patient administration systems were replaced during study (2003-6).
RESULTS
Six main themes emerged from our earlier study:
- The impact of multiple sites resulting from recent mergers
- Poor communication between Connecting for Health and local managers
- The impact of financial deficits
- The need to prioritise performance targets
- Supporting existing “legacy” IT systems
- The delayed timetable for replacement patient administration systems.

Eighteen months later, three of the previous concerns are still apparent (financial deficits, poor communication, and continuing delay) and five new issues were raised:
- Increased support for the overall goals of the programme
- Continuing impact of financial deficits
- Managers distracted from implementing the programme by other priorities
- Continuing poor communication between Connecting for Health and local managers
- Continuing delay in replacing patient administration systems
- Growing risk to patient safety associated with delays
- Loss of integration of components of the programme
- Discontent with Choose and Book.

The eight themes are representative of all 25 staff interviewed. The issues raised were similar among staff interviewed in both phases of the research and those staff interviewed only in the second phase.

Increased support for the goals of the programme
Since the first round of interviews, we found that support for the concept underlying the programme had grown. The overriding view was that the NHS urgently needs the benefits that can be gained from IT modernisation implemented in a standardised way (box 1). We found little resistance to IT modernisation, with interviewees reporting that staff are ready, and sometimes “desperate,” for progress. Alongside this growing support, however, we also found concern about the ability of programme managers to deliver the programme. To maintain momentum, interviewees said that Connecting for Health needed to deliver products that work soon. They also emphasised the need for independent evaluation to measure the benefits and costs (box 2).

Continuing impact of financial deficits
In our earlier interviews, senior staff in trusts facing financial difficulties were concerned about how to pay for the implementation costs associated with IT modernisation. Currently, financial difficulties within the NHS are even more widespread, and this issue has become more important. Respondents reported that making savings is now more critical and that applications that are part of the programme are not the bargain they were expected to be. Implementation of picture archive and communication systems (PACS) is also causing disquiet. Some respondents reported that such applications supplied through the programme seem to be more expensive than market alternatives (box 3), but a central Connecting for Health mandate has left them with no choice but to implement the more expensive option.

Managers distracted from implementing the programme by other priorities
Financial deficits not only cause concern about how to pay for implementation of the programme but also act as distractions for managers. In the earlier interviews, some trust staff reported that recent mergers and the need to prioritise attainment of performance ratings made it difficult to prepare for the programme. Eighteen months later, the priority of trust finances
dominated. Two of our four trusts have had “turn around teams” in place (external consultants brought in to help trusts resolve financial crises). One trust also has the Department of Health’s performance support team working with it. The dominant and immediate need to eliminate any overspend, while maintaining performance, seems to leave managers little time to commit to implementing the programme or any other new services or products (box 4). The programme was reported to be a pressing priority only in trusts where managers perceived a considerable risk to patients’ safety from having to maintain existing legacy systems while waiting for new systems to arrive (see box 8).

Poor communication between Connecting for Health and local managers

Previously, interviewees in all four trusts were concerned with a lack of clarity from Connecting for Health about the timetable for implementation. Eighteen months later, although respondents were enthusiastic about the goals of the programme, the perception of poor communication was unchanged. There is still uncertainty about the timetable for delivery of key components of the programme (such as core hospital administration systems compliant with the hardware and software applications that will make up the programme) and about the extent of financial assistance for “required” components. Respondents reported that much of the decision making has been between Connecting for Health and the local IT service provider. This lack of local involvement seems to have increased feelings of disempowerment and frustration (box 5). The uncertainty has also resulted in some trusts adopting policies that actively discourage staff from engaging with the programme (box 6).

Continuing delay in replacing patient administration systems (PAS)

In the first interviews, respondents were concerned about when their patient administration systems (PAS) would be replaced. Originally, the national programme planned for this system to be installed before any clinical applications. Because of delays in developing a PAS that can achieve connectivity with the “spine” (a nationally accessible summary of patients’ records) this plan has had to be revised and interim off the shelf applications are now being offered. The revised plan has slowed progress, and trusts are still unsure when their replacement PAS will be implemented. Interim applications will allow trusts to move forward to some extent but will not achieve the promised wider connectivity with other NHS hospital trusts and primary care teams (box 7).

Growing risk to patients’ safety associated with delays

Before the programme was conceived, NHS hospitals bought their own IT systems. When first interviewed,
senior clinicians were worried that the replacement of these systems (often carefully customised to meet local needs) might result in a loss of functionality. This concern, though still evident in our recent interviews, has been largely superseded by the urgent need to replace legacy systems. When details of the programme were announced in late 2002, many trusts stopped investing in upgrading their existing IT systems, choosing instead to spend money on other priorities while waiting for the supply of applications compliant with the programme systems. Delays mean that trusts in our study are still waiting for new systems. Where replacement systems were needed in 2002, the delay is now perceived to represent an unacceptable risk to patients’ safety, with trusts considering buying interim systems outside the programme (box 8).

**Loss of integration of components of the programme**

The original goal of access to information across the NHS that underpinned the IT programme seems to have been lost. The lack of integration offered by interim applications has left senior trust staff questioning whether NHS-wide connectivity will ever be achieved and why trusts have had to wait several years for the new systems. The purchase of interim applications does not seem far removed from how the NHS acquired IT before the programme, with the problem of this approach seemingly perpetuated, such as databases that cannot be accessed from outside the trust (box 9). Managers also questioned how the government vision of decentralising clinical services, by increasing provision in the private sector, aligns with the government’s vision of decentralising clinical services, by increasing provision in the private sector, aligns with the NHS IT programme is never closer than two years away and just when you think it’s actually going to be closer it suddenly goes again and it’s two years away again’—systems training manager, trust 3

“I see all the sort of stuff, the propaganda that comes out from CIH and they’re always saying how a lot of these things are actually on time, despite what the press says, hundreds of people are using the new systems and all that sort of, and I must say, you know, there’s not an awful lot of evidence of that across the country, I don’t think”—clinician lead for Connecting for Health, trust 2

“So we’ve got these tactical solutions coming in and that helps because we’re seen to be moving forward. My only problem with tactical solutions is that in a few years’ time one expects that tactical solutions to be replaced with whatever IDX [one of the specialist subcontractors] is going to demand and I don’t know that I really want to put my trust through implementing a tactical PAS and then doing it again”—director of information management and technology, trust 2

**Box 6 | Lack of clinician engagement**

"I’m not driving the national programme forward at all . . . We’re not doing any enabling at all as far as that process is concerned. I’m definitely not going to do what some of my colleagues have and that’s work on the basis that they were getting their slots and have ended up with staff employed, ready to go and nothing to go with”—director of information management and technology, trust 2

"We’ve actively discouraged it here [engagement], which is a strange thing to do, in a way, but because we didn’t want to raise expectations . . . there is no software backing that up at the moment, or not that we’ve seen . . . I don’t encourage our clinicians to get involved on the demonstration days”—director of information management and technology, trust 4

"I wouldn’t go out and sell it to people because I don’t know when it’s going to arrive . . . getting people too enthusiastic on specific timescales would have been very dangerous”—chief executive, trust 4

"I think the biggest problem we’ve had, as an organisation, is, um, you have to have a product to sell to the clinical staff to get them enthused, to get them to use it, and the biggest problem we’ve had is that the product has not revealed itself to us yet”—medical director, trust 3

Choose and Book (patients being able to choose to be referred to one of a range of hospitals) among the staff we interviewed (box 10). The technical problems affecting electronic booking have also undermined confidence in other planned applications. None of the managers or clinicians we interviewed was optimistic about the ability of Connecting for Health to deliver the systems. The doubts expressed were twofold: whether it was technically possible and whether the products would be delivered in a reasonable time frame. Participants expressed feelings of frustration at the slow progress.

**DISCUSSION**

**Key findings**

Over three years from inception, and despite several setbacks and some hostile media coverage, the government’s NHS IT programme remains an objective that many NHS staff support. In line with the National Audit Office report all of our interviewees were enthusiastic about the goals of the programme.

Set against this support were concerns about a lack of clarity and progress. Senior managers need to make financial savings and achieve efficiencies. Although modernisation of IT should facilitate these goals, continuing uncertainty makes key managerial decisions more rather than less difficult. Trusts still do not know what the local costs of implementation will be; when a replacement patient administration system compliant with the programme will be available; the timetable for delivery of interim applications; the features of these applications; and the likely benefits and

**Box 7 | Continued delays and re-planning**

"The dates keep getting re-planned because we’re not allowed to say delayed anymore. We joke in this trust that the NHS IT programme is never closer than two years away and just when you think it’s actually going to be closer it suddenly goes again and it’s two years away again”—systems training manager, trust 3

"They obviously, they know that the CRS [Care Records Service] isn’t going to deliver in a sort of timely manner, so they’re kind of looking at this other product to work with existing PASs”—assistant director of information management and technology, trust 4

"So we’ve got these tactical solutions coming in and that helps because we’re seen to be moving forward. My only problem with tactical solutions is that in a few year’s time one expects that tactical solutions to be replaced with whatever IDX [one of the specialist subcontractors] is going to demand and I don’t know that I really want to put my trust through implementing a tactical PAS and then doing it again”—director of information management and technology, trust 2
efficiencies from new systems (whether interim or planned).

Ministers and senior civil servants have acknowledged that the total cost of the programme will far exceed the current budget of £6.2bn but have not clarified how the additional costs will be met. It is not clear how much more implementation and additional “required components” will cost trusts, nor what cost savings might be expected after implementation. Trusts have also not received guidance on how to maximise possible savings by, for example, redesigning local work practices.

It has been difficult for trusts to prioritise the programme and engage staff when implementation timetables keep shifting. In the meantime, trusts have used a “patch and mend” approach to maintain existing systems. Major concerns over the risk to patients’ safety by continuing this approach have been expressed and reported elsewhere. Trusts are attempting to mitigate the risk by opting for interim systems, although delivery of these interim systems is also delayed. Purchasing interim systems outside the programme is also likely to be inefficient if trusts subsequently have to buy new systems compliant with the programme during the lifetime of the interim system.

The programme in wider context

Although the diversity of healthcare provision in other countries means projects on the huge scale of the national programme for information technology are unlikely, the widespread implementation of electronic healthcare records is progressing elsewhere. France has a national electronic medical patients’ record system planned for introduction in 2007, combining all consultations and procedures, treatments, drugs, and medical devices prescribed. Similarly, Australia is trialling a new national management system for electronic patients’ medical records, called HealthConnect. Creation of the Office of the National Coordinator for Health Information Technology in the United States also indicates a strong commitment from the current US administration to this task.

For these countries, an important lesson to emerge from our study is the difficulty in achieving an appropriate balance of responsibility between government and local healthcare organisations. Devolving control of IT to local managers can result in a lack of standards and local work practices. Although the diversity of healthcare provision in other countries may mean projects on the huge scale of the national programme are unlikely, the widespread implementation of electronic healthcare records is progressing elsewhere.

Box 8 | Concern over growing risk to patients’ safety: some trusts may go it alone

“Our path system is extremely out of date, it’s not just obsolescent, it’s obsolete. When we had to buy some new bits for it recently we had to buy them through eBay from someone in America because there’s just no bits in this country, so it’s a huge risk to the trust that we’re still carrying this path system”—medical director, trust 4

“It’s been urgent that it’s replaced all the time I’ve been here, which is about three and a half years, so I mean the first thing I heard about when I arrived was the fact that the PAS system needed to be replaced. It is a clinical risk”—director of nursing, trust 1

“And there are a number of risks that are associated with our old system, some very serious risks and risks in development and progress within the organisation and between the organisations due to this lack of putting a good idea into practice”—divisional manager for diagnostic therapies and outpatients, trust 4

“Well that’s a risk we, that is a risk. I mean it could, you know, die tomorrow, it’s such an old system and then we are really stuffed, basically”—director of nursing, trust 2

“People are saying ‘Thank God we’re going to get a new system that will replace this load of old, you know, cobbles’… Americans use the expression ‘You need a burning platform to get change.’ Well, I think from an IT perspective we’ve probably got one”—director of information management and technology, trust 2

“One of the options I have is to say ‘To hell with it, I’ll just go and buy one.’ Well, that’s a kind of tricky decision and that’s the decision some of my peers are making elsewhere, they’re saying ‘Well, sod that, I’ll go elsewhere’”—divisional manager for diagnostic therapies and outpatients, trust 4

Box 9 | Loss of integration of components of the NHS IT programme

“I think it is back-peddling big time because I don’t think the, right now they’re in a position to deliver that original vision and so even things like the PACS was going to be an NHS-wide archive and then it was going to be a cluster archive and now they’re just talking about having a trust archive”—director of information management and technology, trust 4

“I’m just wondering that the ideas are actually drifting away from the way that initial strategy, from the way the trust is working, whereas at one time you kind of offered a nice way forward I’m worried it’s kind of diverging”—divisional manager for diagnostic therapies and outpatients, trust 4

“One of the things that’s become apparent is that the original vision of a shared record between primary and secondary care is not at the moment on the, on the design, aim and design… what they’re looking to do is to use messaging systems between primary and secondary care, so effectively you’ll have electronic letters and discharge summaries and those sorts of reports and the spine won’t, the spine is currently going to be quite thin, so it’s not going to be data rich”—clinician lead for Connecting for Health, trust 2

“We’ve got foundation trusts, we’ve got perhaps more importantly the mixed economy so, are we saying that a condition of a private provider receiving NHS work is that they have to be signed up to the national programme?… We’re not going to have a national solution that actually is fit for purpose in a mixed economy and providers”—chief executive, trust 2

“I genuinely am not sure whether the solutions are solutions to yesterday’s analysis rather than today’s analysis… I think what’s happened over the last few years is we have moved from NHS plc to healthcare, as an industry, which has lots of different players in it”—chief executive, trust 3
WHAT IS ALREADY KNOWN ON THIS TOPIC
Concerns have been raised in the national media and elsewhere about the implementation of the NHS IT programme
Last year’s National Audit Office report stated that, while the NHS IT programme has made substantial progress, challenges lie ahead, including delivering systems within agreed timetables, ensuring that NHS organisations fully play their part, and winning the support of NHS staff

WHAT THIS STUDY ADDS
Senior trust managers and clinicians reported concerns about a growing risk to patients’ safety from continuing delays in delivering new IT systems; the cost of interim applications and whether they represent value for money; uncertainty over delivery timetables; and achieving integrated IT systems, as the NHS IT programme original envisaged
Several of these concerns had actually been first expressed over two years ago
Acute hospital trusts cannot prioritise the implementation of the NHS IT programme because of these uncertainties and their need to achieve stringent financial targets

the day to day running of their practices, these systems have been specifically designed to meet their business needs. The systems underpin relatively simple clinical functions, but effectively allow general practitioners to run their practices. They may perceive that they have little to gain from this programme and, importantly, can choose not to have applications of the programme imposed on them.

By contrast, acute hospital trusts have to deal with more urgent and complex demands, requiring fast communication between hundreds of people across many specialties and professional disciplines, yet the IT systems to support this activity are poor. Acute hospitals stand to benefit hugely from modernisation, not least in achieving the efficiencies currently demanded of them. For managers and clinicians in acute trusts, the programme is desperately needed and has to work.

Independent procurement of IT systems, in the absence of national standards, has already been tried with little success.

These difficulties have led to a third, middle way, being tried: setting central standards but with local implementation. As recommended by the British Computer Society, the role Connecting for Health is now shifting away from implementation towards providing a national infrastructure and setting standards. Implementation will now be devolved more locally, as set out in the NHS national business plan for 2007. Even with these changes, the issues raised in our study, particularly in regard to risks to patients’ safety, still need to be urgently addressed.

Strengths and limitations of the study
The small number of participating trusts makes us cautious about generalising our findings. The trusts studied are in only two of the five geographic implementation clusters. Uncertainty over timetables and a lack of progress, however, have been widely reported everywhere. Moreover, mergers of IT companies also means that the trusts studied are being supplied by two of (now) four local service providers.

Concerns raised by respondents about performance and finance are prevalent issues in the NHS but may be more salient in our participating trusts than nationally.

We found no substantive differences in views among staff interviewed in the earlier phase of the study and those interviewed later. Staff interviewed were all senior NHS personnel. The 14 recent employees would probably have been recruited from similar NHS posts elsewhere, suggesting wider generalisability. Another limitation of our study is the lack of a primary care perspective, which we have discussed above.

Set against these limitations, ours is the only in-depth, longitudinal study of modernisation of IT within the NHS. We interviewed a cross section of senior trust staff responsible for implementing the programme in NHS hospitals over a period of two years.

These interviews have provided us with a detailed account of their views about progress, the challenges they perceive in implementing the programme in NHS hospitals, and their information needs in addressing these challenges.

Conclusions
The staff we interviewed were unreservedly in favour of IT modernisation, but this support will quickly diminish unless more progress is achieved. To progress and maintain a vision consistent with the original goals of the programme, Connecting for Health needs to address the uncertainty experienced by trusts and take responsibility for advising about interim decisions.

Trust managers urgently need concrete information about implementation timetables, long term goals of the programme, and value for money. Finally, trusts need help to prioritise IT modernisation against other competing financial pressures—for example, by including it in performance management frameworks.

Box 10 | Discontent with Choose and Book and loss of confidence in the programme

"I've not really talked to the clinicians about, about whether they think it's a good idea or not [Care Records Service]. They certainly think Choose and Book is a crap idea, they hate it"—director of performance and improvement of information, trust 1

"We'll call it Choose and Book because it helps with politics. The software is not fit for purpose . . . We have an unstable middle-ware server because the spine keeps vanishing . . . what happens is the synchronisation messages from them to the other doesn't happen, things get lost, so you end up with patients booked, but we don't know about them . . . We're getting a 53, sorry 57% error rate at the moment"—director of information management and technology, trust 2

"Technically I'm not sure that they can deliver it at the moment . . . I don't think they have the architecture in place to actually deliver it on a national scale, let alone, actually even a cluster scale, to be honest, so I think they are struggling with it"—director of information management and technology, trust 4

"Somebody, not here but at the PCT level, is trying to increase that all the time [usage by general practitioners] . . . I know that some GPs absolutely hate it and I get the impression that they're using it under duress and that the slightest fault is a case of 'Well, what a rubbish system, would never work anyway'"—chief executive, trust 4

"If it doesn't start delivering soon people will begin to say it can't deliver . . . they, they just feel resentment or that it's irrelevant or, worse still, it looks like money poured down the drain while they're having to make staff redundant . . . then there will gradually be a sort of almost a 'We're going to make sure it doesn't work' mentality coming"—chief executive, trust 4
We thank participating trusts, individual interviewees for their time and interest, and members of the steering group for their continuing support.

**Contributors:** JH took part in conducting, planning, and reporting the work. NF took part in planning and reporting and is guarantor. BCR and AH took part in planning and reporting. SC took part in conducting and reporting.

**Funding:** NHS Service Delivery and Organisation R&D Programme (ref. SDO/44/2003).

**Competing interests:** None declared.

**Ethical approval:** NHS Trent multicentre research ethics committee and NHS trust local research ethics committees.

10. Miles MB. Qualitative data as an attractive nuisance—the problem of analysis. Adm Sci Q 1979;24:590-601.
17. Independent audit could be key to success. Computer Weekly 2006;11 April;18.
24. Keen J. The NHS programme for information technology. This massive natural experiment needs evaluating and regulating. BMJ 2006;333:3-4.

Accepted: 17 April 2007
Driving and dementia

David A Breen, David P Breen, John W Moore, Patricia A Breen, Desmond O'Neill

Dementia is important in relation to driving. As the disease progresses the ability to drive safely is eventually lost and at that point current regulations demand that driving stops. Many patients continue to drive after dementia has been diagnosed, however, and withdrawal of their licence should not be undertaken lightly. A study highlighted the negative consequences of stopping people with dementia from driving. Stopping driving can limit access to family, friends, and services and is an independent risk factor for entry to a nursing home.

Traffic medicine has evolved significantly since the 1990s, with more emphasis on preserving mobility. As populations age and increasing numbers of older people drive general practitioners are key players in ensuring that older people are not constrained by an unfair attribution of risk.

Health professionals, however, practise in a society where the perception of older drivers is negative. This may stem from misconceptions about the impact of age related disease on driving: these misunderstandings also apply to medical journals, which commonly reproduce statements on the apparent increase in crashes per mile driven for older people, despite several studies having established that this is related to low mileage rather than to age. Indeed major problems arising out of increasing numbers of older drivers have been shown to be unlikely, with improvements in driving occurring with successive cohorts of older drivers. Surveys of drivers aged more than 80 consistently show prudent driving behaviours. Even the presence of medical conditions is associated with a relatively modest increase in adverse driving events.

Crash data
The risk of crashes in patients with dementia has been extensively studied (table). The over course of the disease evidence suggests that the risk of a crash is significantly increased. As a general rule, however, the risk seems to remain acceptably low for up to three years after the onset of dementia, by which time most patients have stopped driving. A more detailed analysis of data on crash risk in dementia is provided on bmj.com.

Who decides on medical fitness to drive?
Although the Driver and Vehicle Licensing Agency in the United Kingdom has the legal responsibility of deciding on medical fitness to drive, general practitioners and specialists have important parts to play (figure). The Royal College of Psychiatrists and the General Medical Council have gone to considerable efforts to clarify their expectations of reasonable practice. The council is clear that for several conditions (including dementia), doctors should not only advise patients of the possibility of stopping driving but also take steps to ensure that the relevant statutory authorities are informed of breaches of regulation if there is reasonable concern about public safety. Studies have found that psychiatrists have a poor knowledge of the guidelines issued by the Driver and Vehicle Licensing Agency and that relatively few patients are advised that they should not drive, although the reasons for this pattern of advice may be complex.

What should I do in the clinic?
Whenever dementia is diagnosed it is vital to inquire about the driving status of the patient and to maximise traffic related health (for example, checking visual acuity, ensuring arthritis does not affect ability, and reviewing medications). The Driver and Vehicle Licensing Agency states that anyone holding a driving licence must, by law, inform the agency when given a diagnosis of any medical condition that might affect safe driving (box 1). Providing a patient with a pro forma can help with provision of information to the Driver and Vehicle Licensing Agency. Providing written information and advice (such as the leaflet on driving and dementia produced by the Alzheimer’s Society) is also advisable. Clinicians must make an immediate decision on whether the patient is fit to continue driving while further assessment is arranged. All

Sources and selection criteria
We carried out a literature search from 1966 to April 2007 of several electronic databases (Medline, PubMed, CINAHL, Embase, and the Cochrane Library) using the search strategy: [dementia$.ti. OR alzheimer$.ti.] AND [drive$.ti. OR auto$.ti. OR mobi$.ti. OR crash$.ti.] LIMIT to human AND English. The references generated were checked for relevance on the basis of their title and abstract, and we followed up other references from the papers identified. We used the Google search engine to explore the Internet. We also contacted the major stakeholder agencies for relevant information.
It is important to advise patients and their families on an individual basis of the predicted decline in driving ability, although three years from when the disease becomes clinically obvious may be reasonable. This allows patients to plan for when they stop driving and to look for alternative transport options. This in itself is a compelling reason to share the diagnosis of dementia with a patient who drives. Many older people do not, however, consider public transport to be adequate or efficient and often see it as a threat to their security. Clinicians should ask family and friends about specific incompetent driving behaviours such as driving the wrong way round roundabouts, getting lost in familiar areas, miscalculating speed and distances,
and poor judgment. It has been shown that knowledgeable informants can detect dementia reliably and accurately, even in its early stages.\textsuperscript{20,21} Family members can help patients realise that it is no longer safe for them to drive, but family may also have ulterior motives for maximising or, more usually, minimising driving difficulties, of which clinicians should be aware.

A doctor has a duty to inform the licensing authority if there is a reasonable likelihood of danger to other road users when patients will not or cannot inform the agency and continue to drive. Doctors should also check that patients are adhering to the guidelines.

**How does the Driver and Vehicle Licensing Agency make its decision?**

When the Driver and Vehicle Licensing Agency is informed of a diagnosis of dementia a medical adviser requests a report from the relevant doctor. The completion of the report may be aided by input from a specialist in old age psychiatry, geriatrician, or neurologist. For this reason many general practitioners refer patients to specialists in the early stages of disease. Some psychiatrists believe that the forms provided by the Driver and Vehicle Licensing Agency are unsatisfactory.\textsuperscript{24} Difficulties can also arise because completion of the form usually takes place at the time of diagnosis and before the effects of treatment have been established. Depending on the information received, the agency may issue a new licence valid for one year (subject to annual review) or revoke the licence (with the possibility for appeal). A slow response from the agency may mean that patients continue to drive for months before the decision is made.

The agency’s medical adviser may request an on-road driving assessment of the patient. This is generally seen as the ideal means for assessing an ageing driver.\textsuperscript{24} The patient is assessed on a predetermined test route in a vehicle with dual controls. Among other things, the patient is graded on sense about road position, response to road signals, and awareness of other road users (Scottish Driving Assessment Centre, personal communication, 2006). Although drivers with dementia tend to perform at significantly lower levels in this type of test,\textsuperscript{25} a significant minority will perform at an acceptable level. The main drawback of on-road testing is the geographical spread of the 17 testing centres in the United Kingdom, although the numbers are increasing (Driver and Vehicle Licensing Agency, 2006).

Patients with dementia must also inform their insurance company of their diagnosis. Failure to disclose this information may invalidate their policy. The Association of British Insurers has advised that, provided the Driver and Vehicle Licensing Agency is satisfied that someone with a diagnosis of dementia is fit to hold a licence, then he or she should be treated no differently from an applicant without a disability or disease (Association of British Insurers, personal communication, 2006). This situation may change with the accumulation of actuarial data.

**What is the role of cognitive function testing?**

Clinicians can carry out a variety of clinical, cognitive, behavioural, and activities of daily living tests to

---

**Box 1 | Guidelines from the Driver and Vehicle Licensing Agency if medical conditions could affect safe driving\textsuperscript{17}**

**Age**

- Age is no bar to the holding of a driving licence
- Licences are normally valid until age 70, unless restricted to a shorter duration for medical reasons
- The agency requires confirmation at age 70 that no medical disability is present
- All licence applications require a self declaration of medical status by the applicant
- The maximum licence period after age 70 is three years, subject to satisfactory completion of medical questions on the application form

**Dementia**

- The agency must be notified as soon as Alzheimer’s disease or another dementia is diagnosed
- Drivers have an obligation to make such a declaration
- The agency accepts the difficulty of assessing driving ability in Alzheimer’s disease
- Patients with poor short term memory, disorientation, and lack of insight and judgment are almost certainly not fit to drive
- In early Alzheimer’s disease, where sufficient skills are retained and disease progression is slow, a licence may be issued subject to annual review
- A formal driving assessment may be necessary
- A decision on fitness to drive is usually based on medical reports

---

**Clinical pathway for advice on driving after a diagnosis of dementia**

<table>
<thead>
<tr>
<th>Diagnosis of dementia</th>
<th>Does the patient drive?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Advise patient to inform Driver and Vehicle Licensing Agency (DVLA)</td>
</tr>
<tr>
<td>No</td>
<td>Take immediate decision on safety to drive</td>
</tr>
</tbody>
</table>

DVLA informed

- Patient fails to inform DVLA
  - Reiterate advice
  - Advise patient in writing
  - Advise patient of your responsibility to disclose to DVLA
  - Disclose to DVLA

Medical report requested with or without on-road assessment

- Licence revoked with possibility for appeal

Issue new annual licence

Continue driving subject to DVLA annual review

Advise regarding alternative transport options
A medical perspective
A 73 year old man presented to the local adult psychiatric service in June 2000 with a six month history of concentration problems and difficulties with short term memory. His family had a strong history of Alzheimer’s disease in later life. He scored 26/30 on the mini-mental state examination, losing points for orientation and immediate recall. He had no agnosia or topographical disorientation. Evidence was insufficient to diagnose dementia.

He presented to the memory clinic again in August 2001, by which time his short term memory loss had progressed and he relied heavily on his diary and his wife for daily living. He was unable to manage his finances and had grossly impaired numerical skills. He continued to sail his boat, but always with the support of an experienced sailor. His score on the mini-mental state examination was now 23/30. A diagnosis of Alzheimer’s disease was made and he was given donepezil 5 mg daily. He continued to drive, which his wife thought he did competently. He was informed of his legal obligation to inform the Driver and Vehicle Licensing Agency of his diagnosis.

When he was seen at the memory clinic in December 2001 he was still driving. No concerns were expressed by his family about his driving ability. He had failed to contact the Driver and Vehicle Licensing Agency as advised.

The patient was advised of his responsibility to inform the Driver and Vehicle Licensing Agency both verbally and in writing. He eventually informed the licensing agency in April 2002. In May 2002 his mini-mental state examination score was 21/30. In June 2002 the medical report from a consultant psychiatrist indicated that the patient had evidence of cognitive impairment and significant loss of judgment. The report also mentioned that the patient had driven into a kerb and punctured a tyre. His licence was withdrawn by the Driver and Vehicle Licensing Agency.

The patient’s wife complained to the licensing agency in late July 2002, after the couple decided that the decision was “ridiculous.”

The patient appealed against the decision. In August 2002 he was granted a provisional disability assessment licence to allow an on-road driving assessment to be completed. In June 2003, 22 months after the diagnosis of Alzheimer’s disease, the patient received an appointment for an on-road driving test, which he failed.

Relicensing for drivers with dementia in the European Union and North America
The European Council directive 91/439/EEC sets out the minimum standards of physical and mental fitness to drive at any age. It makes no specific reference to dementia and so interpretation varies significantly between member states. The subject of relicensing was comprehensively investigated in 2000, with all 15 contemporary EU members surveyed.21 The United Kingdom was the only EU country in which patients had an obligation to inform their driving authority when an illness was diagnosed that may affect driving ability. A system that relies heavily on self reporting can face difficulties in conditions such as dementia where patients are unaware of their compromised driving ability.

State governments in the United States have a variety of methods for increasing the stringency of the licensing process for older people, including the adoption of in-person renewal requirements, vision tests, road tests, and a shorter renewal period.22 In Canada most states have mandatory reporting requirements.23

Conclusions
Some patients with early dementia are capable of driving safely. The three year rule, which broadly states that with regular review the risk of crashes in patients with Alzheimer’s disease is acceptably low for up to three years after the disease becomes clinically apparent, has been proposed as a means of guiding relicensing policy. Whatever the relicensing rules, doctors in the United Kingdom must ensure that the Driver and Vehicle Licensing Agency is informed of all new diagnoses of dementia. They must also adequately complete a medical report, on which the licensing agency will base its decision on fitness to drive. The challenge for doctors and the licensing agency is to balance mobility and safety in the growing proportion of older people in the population. To this end the UK Department of Transport is to launch a public consultation to consider changes to relicensing. Current evidence from Scandinavia, Australia, and the United States, however, suggests that mass medical screening or cognitive screening of older drivers has negative consequences for public health.24 Therefore the main thrust of future measures should focus on opportunistic screening of high

accurately complete the Driver and Vehicle Licensing Agency report, and these tests are well described in the literature.17 18 Although statistically significant differences in cognitive function testing have been shown between dementia groups and controls, overlap between group scores make these tests unusable. This reflects in part the differences in the cognitive deficits between dementia subtypes, a failure to observe and examine these separately in research studies, and great variability in the presentation and course of the dementias. Indeed it is reasonable to say that few, if any, of the tests have any congruence with modern thinking on models of driving behaviour.25 26
The challenge for doctors and the licensing agency is to balance mobility and safety in a growing population of older drivers, risk populations, such as those attending memory clinics, and the refinement of effective pathways for clinicians and the Driver and Vehicle Licensing Agency to manage mobility and safety, a position recently adopted by the House of Lords Science and Technology Committee.

We thank the patient who consented to his case study being published, Eric Wood for his support and advice, the Driver and Vehicle Licensing Agency and the Department for Transport for their assistance, and the medical illustration department at the Royal Infirmary of Edinburgh for formatting the original clinical pathway diagram.

### ADDITIONAL EDUCATIONAL RESOURCES

**Patient and carer information**

- Alzheimer's Society (www.alzheimers.org.uk/After_diagnosis/Driving_and_travelling/info_driving.htm)—Advice and contact details for Driver and Vehicle Licensing Agency and driving assessment centres
- Alzheimer Scotland (www.alzscot.org/pages/info/driving.htm)—Advice on rules of driving with dementia, transport options, and contact details, including dementia helpline
- Driver and Vehicle Licensing Agency (www.direct.gov.uk/en/Motoring/index.htm)—Rules on licensing and updating licences
- Forum of mobility centres (www.mobility-centres.org.uk)—Location and functions of the 17 UK driver assessment centres
- Assessment of medical fitness to drive
- Drivers Medical Group (www.dvla.gov.uk/media/pdf/medical/aagy1.pdf)—Regularly updated state of the art and practical guides to driving

**Carter T. Fitness to drive: a guide for health professionals.** London: RSM Press, 2006—Published on behalf of the Department for Transport and in association with the BMA Canadian Medical Association (www.cma.ca/index.cfm/ci_id/18223/la_id/1.htm)—Up to date advice, with driving and dementia toolkit
- American Medical Association (www.ama-assn.org/ama/pub/category/10791.html)—Guide for physicians on assessing and counselling older drivers

**Older people and transport**

- Transportation Research Board (www.gulliver.trb.org/publications/conf/reports/cp_27.pdf)—Overview of all aspects of transport in older people, with emphasis on North America

**SUMMARY POINTS**

Many people with early dementia are capable of driving safely. Evidence suggests that the risk of crashes in drivers with dementia is low for up to three years after disease onset, but this varies between people. The Driver and Vehicle Licensing Agency must be notified of all new diagnoses of Alzheimer’s disease and other dementias: this relies primarily on self-reporting. The doctor’s role is to make an immediate decision on safety to drive and to ensure that the licensing agency is notified. Cognitive testing cannot determine whether individuals with early dementia are able to drive safely.
NICE GUIDELINES

Management of faecal incontinence in adults: summary of NICE guidance

Christine Norton,1 Louise Thomas,2 Jennifer Hill,2 on behalf of the Guideline Development Group

Why read this summary?
The prevalence of faecal incontinence in adults living in the community is 1-10%, depending on the definition used.1 2 Faecal incontinence is a neglected problem that receives limited medical attention, and despite its profound negative impact most patients do not tell their doctor about it.3 4 Simple, low cost interventions will often improve or even cure symptoms. More sophisticated second line investigations and treatments are available, but referral for these is not common. This article summarises the most recent guidance from the National Institute for Health and Clinical Excellence (NICE) on managing faecal incontinence in adults.5

Recommendations
NICE recommendations are based on systematic reviews of best available evidence. When minimal evidence is available, a range of consensus techniques is used to develop recommendations. In this summary, recommendations derived primarily from consensus techniques are indicated with an asterisk (*).

General approach
All staff working with people with faecal incontinence should be aware of the physical and emotional impact this condition can have on patients and their carers. Consider patients’ needs and preferences when planning treatment and ensure they have the opportunity to make informed decisions in partnership.

Assessment
Healthcare professionals should actively yet sensitively inquire about symptoms of faecal incontinence in high risk groups (box).

Faecal incontinence often has several contributory factors. Assumptions that it is caused by a single primary condition are therefore not appropriate.* Before starting treatment, perform a focused baseline assessment as follows*: • Identify contributory factors from a medical history, general and anorectal examination, and, if appropriate, cognitive assessment • Differentiate between symptoms of urge or passive faecal incontinence and the patient’s normal bowel habit (note any changes) • Assess diet; medical and obstetric history; lifestyle; mobility; and medications • Assess anorectal abnormalities and function or rectal loading by visual inspection and digital examination.

Management
Treat the following specific conditions (if identified from the assessment), before progressing to more general measures*: • Faecal loading (treat with rectal or oral medication until the rectum is empty) • Treatable causes of diarrhoea (for example, infective, inflammatory bowel disease, and irritable bowel syndrome) • Warning signs for colorectal cancer (for example, rectal bleeding, unexplained change in bowel habit, and anaemia)• • Rectal prolapse or third degree haemorrhoids • Acute injury to the anal sphincter (will often need surgical repair) • Cauda equina syndrome or acute disc prolapse.

Once the above conditions have been excluded or treated, offer initial conservative measures, tailored to the patient’s presenting symptoms, as follows: • Try to improve the patient’s bowel habit, aiming for an ideal stool consistency and satisfactory bowel emptying at a predictable time.6 Patient education may help to establish a bowel routine (such as going to the toilet after a meal to capitalise on the gastrocolic response), optimise evacuation (posture and pushing without straining), and regulate diet and fluid intake. Some patients will benefit from modifying fibre intake (an increase or decrease, depending on existing diet and stool consistency), reducing caffeine, and ensuring easy access to a toilet* • Thoroughly review both prescribed and over the counter medications.* Side effects of constipation or loose stools can underlie faecal incontinence. Loperamide hydrochloride is the antidiarrhoeal drug of first choice for faecal incontinence associated with loose stools when relevant investigation and treatment have failed to resolve the loose stools. Start at a low dose, and increase until symptom control is achieved without troublesome constipation (the syrup formulation should be considered for doses under 2 mg). Loperamide hydrochloride can be used in doses up to 16 mg a day on a continuous basis, but...
many patients need a much lower dose or can use only as needed

- Advise on coping strategies, such as the use of continence products (pads or plugs), skin care, and access to emotional and psychological support.*

If symptomatic patients do not wish to continue active treatment or have intractable symptoms*:

- Advise on how to preserve dignity and independence (such as toilet access and use)*
- Offer psychological support, with referral to counsellors or therapists as appropriate
- Review symptoms at least every six months
- Discuss other management options (including specialist referral)
- Provide contact details for relevant support groups
- Provide information and advice on continence products, and provide information on choice of products and their availability and use
- Advise on skin care
- Discuss how to talk to friends and family
- Discuss coping strategies, such as planning routes around public conveniences when travelling.

**Specialist referral**

If symptoms continue, consider referral to a specialist continence service for options such as a pelvic floor re-education programme, bowel retraining, specialist dietary assessment and management, biofeedback, electrical stimulation, or rectal irrigation.* These interventions will usually need to be individually tailored and monitored closely (for example, by digital reassessment). Some of these treatments may not be appropriate for people who cannot understand and/or comply with instructions. Pelvic floor re-education programmes, for example, may not be appropriate for those with neurological or spinal disease or injury that results in faecal incontinence.*

If specialised investigation is needed, a combination of anorectal physiology tests and endoanal ultrasonography will assist selection of patients for surgery.* Where endoanal ultrasonography is not available, magnetic resonance imaging or endovaginal ultrasonography and perineal ultrasonography may be considered.*

Refer patients considering surgery to a specialist surgeon to discuss the potential benefits and limitations of surgical and non-surgical options, particularly long term expectations of effectiveness. Most surgery should be conducted in specialist centres. Anal sphincter repair has limited long term efficacy and should be reserved for patients with major symptoms and an external anal sphincter defect of 90 degrees or more. Neosphincters, such as an implanted inflatable artificial anal sphincter or a transposition of the gracilis muscle around the anus, are generally associated with high complication rates (such as infection, erosion, or equipment failure); no long term data are available yet for sacral nerve stimulation. Training and long term support are needed when implants are used.*

### Specific groups

Adopt a proactive approach to bowel management for the following patient groups, who are prone to faecal incontinence or constipation*:

- People with faecal loading or constipation
- Acutely unwell and hospitalised patients
- Patients with neurological or spinal conditions
- Patients with limited mobility
- Severely or terminally ill people
- Patients with acquired brain injury, learning disabilities, or other cognitive or behavioural problems.

### Overcoming barriers

The most crucial barriers to implementing this guideline may be traditional taboos associated with discussing defecation and the stigma of faecal incontinence. Many people (including some health professionals) do not find it easy to talk about this subject. Local and national campaigns may raise awareness and help to break down taboos on discussing bowel function.

As a symptom, faecal incontinence does not fall under the responsibility of any one professional group. A multidisciplinary approach is recommended.* Most nurse continence advisers focus on urinary incontinence, and many of them may need additional training to take a lead on faecal incontinence. Specialised investigation and management facilities are also lacking.

Although most of this guideline is based on consensus methods rather than high quality research evidence, the guideline development group believes that the commonsense recommendations it contains provide a practical approach to managing the common and neglected problem of faecal incontinence. We hope this guideline will stimulate both clinical and research interest in this topic, and that future updates will have an expanded evidence base on which to work.

---

**References**

**INTERACTIVE CASE REPORT**

A patient with suspected miscarriage is found to have hypertension, renal failure, and thrombocytopenia: case presentation

Chris M Laing,1 Rhys Roberts,2 Liz Lightstone,3 Alison Graham,4 Terry H Cook,5 Shaun Summers,3 Charles D Pusey4

A 46 year old white woman presented to her local casualty department. She had been experiencing vaginal bleeding for 10 days, and the bleeding had become particularly heavy in the past three days. She had also felt generally unwell for around a week with malaise, fatigue, headaches, anorexia, and vomiting.

She and her partner had been trying to conceive. Her last menstrual period had been 10 weeks ago and she had recently tested positive with a urinary (β human chorionic gonadotrophin) pregnancy testing kit. She had three children from a previous partner. Two of these pregnancies were complicated by hypertension from 36 weeks onwards. She thought that she may have had two miscarriages the previous year, which had not been investigated.

The previous year she had a measured blood pressure of 165/90 mm Hg. She gave a history suggestive of Raynaud’s syndrome but had no other symptoms or past medical history of note. She was taking no regular medication.

She was initially referred to the on-call gynaecologist who found her to have a blood pressure of 240/127 mm Hg and a heart rate of 100 beats/minute. She appeared unwell and was dyspnoeic at rest. On abdominal examination the uterus was not palpable, and on vaginal examination the cervical os was open and bleeding. Chest auscultation demonstrated bi-basal, inspiratory crepitations. No other abnormalities were found on examination. Urinary β human chorionic gonadotrophin was negative. Urinalysis showed large amounts of blood and protein, but the patient was actively bleeding from the vagina when this test was done. The table shows the results of her laboratory tests.

She was referred for an urgent medical opinion. A central venous line was inserted and a chest radiography performed (figure). At this point, while still in the casualty department, she had several generalised tonic-clonic convulsions.

### Patient’s laboratory test results at presentation

<table>
<thead>
<tr>
<th>Blood test</th>
<th>Result</th>
<th>Normal range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Haemoglobin</td>
<td>10.0 g/l</td>
<td>11.4-14.2</td>
</tr>
<tr>
<td>White blood cells</td>
<td>15.4x10^9/l</td>
<td>6-11</td>
</tr>
<tr>
<td>Platelets</td>
<td>40x10^9/l</td>
<td>150-450</td>
</tr>
<tr>
<td>Reticulocytes</td>
<td>6.2%</td>
<td>0.49-2.03</td>
</tr>
<tr>
<td>Mean cell volume</td>
<td>88 fl</td>
<td>83-101</td>
</tr>
<tr>
<td>Prothrombin time</td>
<td>10.4 s</td>
<td>9.6-11.6</td>
</tr>
<tr>
<td>Thrombin time</td>
<td>14 s</td>
<td>15-19</td>
</tr>
<tr>
<td>Activated partial thromboplastin time</td>
<td>19 s</td>
<td>24-32</td>
</tr>
<tr>
<td>Sodium</td>
<td>132 mmol/l</td>
<td>135-145</td>
</tr>
<tr>
<td>Potassium</td>
<td>3.2 mmol/l</td>
<td>3.5-5.0</td>
</tr>
<tr>
<td>Urea</td>
<td>22.4 mmol/l</td>
<td>2.5-6.4</td>
</tr>
<tr>
<td>Creatinine</td>
<td>387 µmol/l</td>
<td>56-98</td>
</tr>
<tr>
<td>Albumin</td>
<td>29 g/l</td>
<td>30-50</td>
</tr>
<tr>
<td>Calcium</td>
<td>1.73 mmol/l</td>
<td>2.15-2.6</td>
</tr>
<tr>
<td>Phosphate</td>
<td>2.09 mmol/l</td>
<td>0.8-1.5</td>
</tr>
<tr>
<td>Bilirubin</td>
<td>31 µmol/l</td>
<td>2-17</td>
</tr>
<tr>
<td>Alkaline phosphatase</td>
<td>55 µ/l</td>
<td>30-130</td>
</tr>
<tr>
<td>Alanine transaminase</td>
<td>13 µ/l</td>
<td>0-31</td>
</tr>
<tr>
<td>Aspartate transaminase</td>
<td>39 µ/l</td>
<td>8-35</td>
</tr>
<tr>
<td>Lactate dehydrogenase</td>
<td>2846 µ/l</td>
<td>85-285</td>
</tr>
<tr>
<td>Glucose</td>
<td>6.7 mmol/l</td>
<td>4-6</td>
</tr>
<tr>
<td>Chloride</td>
<td>94 mmol/l</td>
<td>95-105</td>
</tr>
<tr>
<td>pH</td>
<td>7.34</td>
<td>7.35-7.45</td>
</tr>
<tr>
<td>Partial pressure of carbon dioxide</td>
<td>3.99</td>
<td>4.7-6.0</td>
</tr>
<tr>
<td>Partial pressure of oxygen (fractional inspired oxygen 40%)</td>
<td>23.28</td>
<td>10-13</td>
</tr>
<tr>
<td>HCO3</td>
<td>14.5</td>
<td>22-30</td>
</tr>
<tr>
<td>Base excess</td>
<td>−12.4</td>
<td>2 to +2</td>
</tr>
<tr>
<td>β Human chorionic gonadotrophin</td>
<td>Negative</td>
<td></td>
</tr>
<tr>
<td>Blood film</td>
<td>Moderate red cell fragmentation, platelets low</td>
<td></td>
</tr>
</tbody>
</table>

She was initially referred to the on-call gynaecologist who found her to have a blood pressure of 240/127 mm Hg and a heart rate of 100 beats/minute. She appeared unwell and was dyspnoeic at rest. On abdominal examination the uterus was not palpable, and on vaginal examination the cervical os was open and bleeding. Chest auscultation demonstrated bi-basal, inspiratory crepitations. No other abnormalities were found on examination. Urinary β human chorionic gonadotrophin was negative. Urinalysis showed large amounts of blood and protein, but the patient was actively bleeding from the vagina when this test was done. The table shows the results of her laboratory tests.

She was referred for an urgent medical opinion. A central venous line was inserted and a chest radiography performed (figure). At this point, while still in the casualty department, she had several generalised tonic-clonic convulsions.

### Questions

1. Would investigation for recurrent miscarriage have been appropriate given the patient’s reproductive history, and if so, how?
2. What diagnoses might explain the patient’s presentation and the abnormalities found?
3. What could account for the patient’s chest radiography results?
4. Outline how the patient should be investigated and managed during the first 24 hours

Please respond through bmj.com, remembering that the patient is real and that she and her carers will read the response.

---

**Institute**

1 Critical Care and Internal Medicine, Department of Medicine, University College London Hospital, London NW1 2BU
2 Department of Medicine, Hammersmith Hospital
3 West London Racial and Transplant Centre, Hammersmith Hospital
4 Department of Radiology, Hammersmith Hospital
5 Division of Investigative Science, Imperial College London, Hammersmith Hospital Campus, London W12 ONN
6 Division of Medicine, Imperial College London, Hammersmith Hospital Campus

**Correspondence to:** C M Laing

christopher.laing@mac.com

**BMJ 2007;334:1372 doi: 10.1136/bmj.39212.564745.BE**

---

**This is the first of a three part case report, where we invite readers to take part in considering the diagnosis and management of a real patient using rapid responses on bmj.com. In four weeks’ time we will report the outcome and summarise the responses.**

**We welcome contributions of interactive case reports. Cases should raise interesting clinical, investigative, diagnostic, and management issues but not be so rare that they appeal to only a minority of readers. Full details of criteria are available at: bmj.com/cgi/content/full/326/7389/564/DC1**

---

**Competing interests:** None declared.

**BMJ | 30 JUNE 2007 | VOLUME 334**
How to avoid an e-headache

**PERSONAL VIEW Joan S Ash**

The scope and boldness of the National Health Service’s Connecting for Health initiative are unprecedented. While nations worldwide have set health information technology as a high priority to combat medical errors and increase efficiency, England has outlined the most courageous goal of this kind, aiming towards a national electronic health record service. Implementing systems nationwide, or even regionally, is extremely difficult, yet England is making admirable progress and essential iterative adjustments. Ongoing evaluation efforts, such as those described in Hendy and colleagues’ study in this week’s BMJ, are necessary to guide such adjustments. Temporary setbacks are inevitable and we must learn from them.

Why is implementation of health information technology such a universally difficult process? It is because we are transforming health care through information technology rather than simply automating old processes. Workflow and work life must change, which means people must adapt. Such change is deeply disruptive. The related personal and organisational challenges are enormous, yet efforts to manage change receive inadequate attention and funding.

How can we succeed in such implementations of information technology? Firstly, we must define success explicitly and understand that our goal is long term, and that we will inevitably stumble along the way. Many, perhaps most, successful implementations of clinical systems have been preceded by suboptimal ones, yet these are too often concealed. We must begin to share these experiences openly and cherish these opportunities to learn how to improve implementation efforts. Boldness breeds occasional blunders, which can teach us much about what is required for eventual success.

Secondly, we must expand knowledge about best practices for implementation in different settings. Informatics is the discipline that considers the effective organisation, analysis, management, and use of information in health care. Educational programmes in informatics aim to produce people who understand both the clinical and the information technology worlds, so that they are especially well prepared to implement systems sensitively. There is now a body of evidence about success factors for implementing clinical systems (see, for example, www.cpoec.org), and several major categories of success factors have been verified repeatedly.

The use of skilled project management techniques is one of the most important and perhaps the most applicable factor in implementing the NHS efforts. Defining the scope of any project is a first step, and any expansion of scope, such as delivery of an email system not originally planned, must be carefully considered and funded. When politics enter the picture, the tenets of good project management can become threatened. The foundations of project management—resources, schedules, and performance outcomes—are like the legs of a three legged stool: if one leg is weak, the stool might collapse. Cuts in resources must result in adjustments to schedules and performance expectations. Another relevant aspect of project management is that the leadership attribute of steadfastness is paramount. Stable, brave, bold leadership is needed to overcome the stumbles and seek the long term goals, even if the political environment at times interferes. Finally, ongoing evaluation and monitoring of the impact of new systems are necessary for project success.

Impatience is risky, and there is even greater danger in judging a large complicated project before it has had time to evolve and mature. In the United States, we are envious of the NHS’s performance in implementing electronic records in primary care, and we are watching development of “the spine,” the centralised care record, with great interest. There is no doubt that implementing state of the art health information technology is the right thing to do. Wisdom, perseverance, and fortitude are all needed to overcome inevitable problems. Connecting for Health is making progress, but we must be mindful of the words of Winston Churchill in 1942, after the British victory at El Alamein: “Now this is not the end. It is not even the beginning of the end. But it is, perhaps, the end of the beginning.”

Joan S Ash is associate professor, Department of Medical Informatics and Clinical Epidemiology, School of Medicine, Oregon Health and Science University, Portland, Oregon, USA ash@ohsu.edu
NETLINES

With the ban on smoking in public places in England coming into force on 1 July, many smokers will need support to quit. Online support is available at the well designed site www.packitin.org. Registration at the site costs £10 for three months, a relatively modest fee in comparison with the price of cigarettes. The site has several support tools and tries to generate a sense of community—for example, through chat rooms. The features include an “Ask the doctor” section and a calculator that shows how much you have saved by not smoking.

Another smoking cessation site, which carries NHS branding, is www.smokefree.co.uk. Neatly combining online resources with more traditional offline support such as a telephone helpline and links to users’ local facilities, it is an informative and helpful site for people who are considering quitting. Its logical layout guides smokers through the steps to quitting smoking and offers answers to questions that a typical smoker may ask. There is also a secure online form to ask an expert a question. This is an excellent and user-friendly facility.

Although the web is full of clever and flashy websites covering contemporary and fashionable topics, simple websites concerned with historical issues can still be effective. Take the website of the National Museum of Civil War Medicine in Maryland and in particular www.civilwarmed.org/collections.cfm, which gives a fascinating insight into the lives and times of doctors who practised in the American civil war. The text is not long and is accompanied by good illustrations.

The internet is an ideal place to store and distribute information from the fast moving area of adverse drug reactions. One fine example of this is the Australian Adverse Drug Reactions Bulletin, which is published every two months and is freely available at www.tga.gov.au/adr/aadrh.htm. As is often the case these days the bulletin is published as a PDF file (although HTML versions are also available), and the online archive extends back to 1995. With the most recent edition published at the top of the home page, it is easy to keep up to date with the latest thinking on adverse reactions.

Harry Brown general practitioner, Leeds DrHarry@DrHarry.net

We welcome suggestions for websites to be included in future Netlines. Readers should contact Harry Brown at the above email address.

REVIEW OF THE WEEK

Sex and drugs and rock and roll

The long awaited revamp of the Wellcome Collection, which claims to be the world’s first public venue devoted to looking at the human condition, impresses Colin Martin

The Wellcome Collection
83 Euston Road, London NW1 2BE
www.wellcomecollection.org
Rating: ★★★★★

Steve Cross, one of the head curators at the Wellcome Collection, which has just undergone a £30m (£45m: $60m) facelift and reopened to the public last week, is impressed by the zeal of the collection’s namesake. “It’s strange to think that as well as building up one of the world’s biggest pharmaceutical companies from scratch, Sir Henry had time to organise archaeological digs and run an army of collectors and curators scouring the world for interesting objects,” he said.

The reorganised collection is located in the Wellcome Building, the Wellcome Trust’s former headquarters in Euston Road, London. Built in 1931-4 by Henry Wellcome (1853-1936) to house his collection, library, and laboratories for research into tropical medicine, it has been sensitively transformed over the past five years by Hopkins Architects.

Born in the US Midwest, Sir Henry was a pharmacist, entrepreneur, philanthropist, and collector. In 1880 he established the Burroughs-Wellcome pharmaceutical company in the United Kingdom with Silas Burroughs. Sir Henry became sole owner when Burroughs died in 1895, and he used a large part of the company’s profits to collect more than a million medical, cultural, and anthropological objects from around the world. In his will he set up the Wellcome Trust, currently the world’s second largest medical research charity, with investment assets of £14bn. This year it will spend £540m to support biomedical research and encourage public debate about the importance of research.

“The Wellcome Collection has 1300 to 1500 exhibits on show, depending on how you count them,” said Ken Arnold, head of public programmes at the Wellcome Trust, who led the curatorial team responsible for developing exhibitions for the three dedicated galleries in the remodelled building.

The Medicine Man gallery displays 500 artefacts from Sir Henry’s original collection. Its designer, Gitta Gschwendtner, by using US walnut fittings in homage to Sir Henry’s original offices at Snow Hill, has created an evocative space with a 1930s ambience. She also used cutout wooden capital letters to label the display cases, in a witty reference to art deco shop design.

The exhibition is an edited version of one held at the British Museum in 2003; however, this time the focus is on the categories of objects Sir Henry...
Henry collected rather than on the human body itself.

One of the most striking displays consists of artificial limbs, arranged as legs and arms marching through a glass vitrine, like a disembodied army. In addition to artefacts, a 2002 film by the Brothers Quay called Phantom Museum: Random Forays into Sir Henry Wellcome’s Medical Collection takes an idiosyncratic look at the part of his collection stored by the Science Museum.

The Medicine Now gallery explores contemporary topics in medicine through science, art, and popular culture. Topics covered are the human genome, the human body, malaria, obesity, and the experience of medicine. Also designed by Gschwendtner and curated by Dr Cross, the gallery’s radical style catapults visitors into the 21st century. Art exhibits are displayed within large red cubes, which function as mini-galleries within the larger gallery. This arrangement separates the works of art from the scientific and medical exhibits that have been selected to provide additional insight into the topics, which are displayed on theatrically oversized shelves.

Sited throughout the gallery are “Sit down to hear...” chairs, activated by someone sitting on them and providing audio commentaries recorded by experts from relevant disciplines. It seems that the designer and curator missed a trick by not installing a treadmill operated commentary in the gallery’s obesity section in front of John Isaac’s I Can’t Help the Way I Feel (2003), a lard-like sculpture of a shockingly obese figure almost engulfed in its own mass.

The malaria section includes Veil of Tears (2007), a newly commissioned work by the artist Susie Freeman and the GP Liz Lee, which highlights the burden of malaria during the first five years of life for a child living in a town near Lake Victoria. It’s an installation of four draped bed nets, linked by streamers of tiny colour photographs, stitched into lengths of net ribbon. Entrapped in the bed nets are individual multicoloured, foil wrapped tablets, stained microscope slides, and tiny metal wire mosquitoes, each identified by numerals written in red ink on tiny pieces of paper. Wax models of insects that are vectors for a range of tropical diseases, originally commissioned for the opening exhibition of the Wellcome Museum of Medical Science, allude to an earlier manifestation of Sir Henry’s collection.

“In the developed world we’ve conquered major diseases and started killing ourselves through overeating instead,” said Dr Cross, head curator of the Medicine Man gallery, on the different healthcare challenges in the developing and overdeveloped worlds.

The third and largest Wellcome Collection gallery will stage four temporary exhibitions a year, presenting newly commissioned works and thematic shows on topics of medical, cultural, and ethical significance. The opening exhibition (until 16 September) is The Heart. It traces the history of medical understanding of the organ and also examines its symbolic and cultural significance. A worn and incomplete 18th century Italian wooden statuette of Mary, her torso and heart pierced with seven swords, now resembles a bizarre punk saint yet was venerated in religious processions.

The exhibition’s centrepiece is a display of hearts taken from different animal species, including one removed earlier this month from a 22 year old woman during a heart transplantation operation at Papworth Hospital, Cambridge. The co-curators James Peto and Emily Jo Sargent bought the stuffed shrew, which is part of the comparative display, on e-Bay for £30. At the height of his collecting, Sir Henry was spending more than the British Museum’s annual budget for acquisitions each year. It is fitting that his collecting spirit lives on and that Wellcome Collection curators are using new technologies astutely. Goodness knows how many items Sir Henry would have collected had e-commerce been available to him.

As well as displaying work from its holdings and commissioning new work, the Wellcome Collection also acts as a visual resource for artists and others internationally, through its collection of 200,000 images [http://images.wellcome.ac.uk]. A good example of such work is Tools of the Trade (2003), a series of 21 starched white cloth squares thermally printed with images taken from scientific journals in the Wellcome Library, in which the Australia based artist and midwife Kate Lohse explores “the historical struggle between midwives and medical men for the control of childbirth.”

Visitors to the Wellcome Collection also encounter a striking series of “satellite exhibits” displayed throughout the building. In the ground floor lobby is Marc Quinn’s Stelvia Pettetti—Sustiva Tenofovir (2003), a whistful, life sized sculpture of a reclining woman, cast from polymer wax and drugs. Christine Borland’s A Treasury of Human Inheritance, Worster-Drought’s Case (Possible Congenital Suprabulbar Paresis) (2007), a mobile constructed from delicately coloured agate slices, hangs elsewhere in the building.

“We believe we’ve been true to Sir Henry Wellcome’s vision, with a contemporary twist,” concluded Clare Matterson, director of medicine, society, and history at the Wellcome Trust. “It’s the world’s first public venue that looks at the human condition.” Matterson is optimistic that the Wellcome Collection, which has an annual budget of £2m, will achieve its visitor target of 100,000 during its first 12 months of operation. Audience market research will provide another measure of its success.

The Wellcome Collection ticks the boxes for sex and drugs. The venue looks set to rock too, with a members’ club, cafe, and bookshop and a compelling programme of public events.

Colin Martion is an independent consultant in healthcare communication, London  Cmpubrel@aol.com
**Talk the talk**

“We had ‘the talk’.” I blushed. My 10 year old daughter had just had her first sex education class. My sex education involved somebody’s big brother graphically describing sexual intercourse to hunched groups of ashen faced and goggled eyed 12 year olds in the first few weeks of secondary school. Our formal “sex education” involved a grainy black and white video of a woman giving birth, while we were supervised by a terrified science teacher caught in the headlights of adolescent questioning. I couldn’t speak to my parents for three weeks. We are a modest nation.

On holiday campsites this summer less modest Europeans will be wandering naked in the shower block, standing too close to us, and openly discussing their sex lives. We Brits on the other hand will be tightly wrapped in towels and will double lock the cubicle doors. The United Kingdom is comfortable with this splendid naked isolationism and the sexual innuendo that goes with it. So should I discuss the “birds and the bees” with my children?

The government is trying to reduce teenage pregnancies, but despite its best efforts there has been only a 10% fall in underage pregnancy rates since 1999. Our rates remain three times higher than in the Netherlands.

Teenage pregnancy is concentrated in the inner cities and is strongly associated with poverty, low educational achievement, and the cycle of social exclusion—the scourges of our Anglo-American economic system.

Different countries have tackled teenage pregnancy differently. The Americans flirt with celibacy programmes, such as the Silver Ring Thing (see BMJ 2004;328:292) but this seems pointless and a type of mass hysterical denial. Our own initiatives focus on improving sex education and providing local specialist youth health services. This may have limited impact but at least it is pragmatic. One criticism is that we could do more to engage with young men, but this would mean challenging the comfortable stereotype of male sexuality.

It is those naked Europeans who have been the most successful in limiting teenage pregnancies. They seem to have a maturity and openness about sex that we lack. So we need to spare our parental blushes, for much of the UK solution involves taking responsibility for educating our own children about sex. The key is presenting sex in the context of relationships, rather than as some unreal achievement, and the cycle of social exclusion—the scourges of our Anglo-American economic system.

**Africa**

My auntie, Kate Fitzgerald, lives in Cork and I live in Belgrade. I have to juggle flights, family, and pressing work deadlines to reach her nursing home in a small village so as to have a clear two hours to spare for the visit.

Auntie Kate—the fearless Irish nun and missionary surgeon who ran district hospitals in Nigeria and Malawi. Deceptively small and pious, she had seemed the epitome of glamour and feistiness and had inspired my dream of working as a doctor in Africa—a dream I nurtured for years through medical school and junior doctor jobs in child health, obstetrics, and tropical medicine. A dream watched over by a little wooden elephant that I still keep on my dresser. Circumstances and choice had led me to another reality and another busy and interesting life.

I rush in the door to be stopped in my tracks; the matron tells me that Auntie Kate now usually sleeps until midday and has only just got up. Slowly, slowly they arrange her morning finery.

Our time clocks meet. Mine threatens to race past her until I put on the brakes; hers speeds up as she has a visitor. An aide wheels her to a sitting room, and another age passes while we organise her hearing aids. There she sits, 84, blind and almost completely deaf, frail as a waif.

She recognises my voice, and to see such a warm smile on a blind old lady’s face is as good as watching your small child smile in its sleep. We hold hands and she feels my face a little and then we talk.

Phrases and stories bubble to the surface half formed. The children and mothers, the hospitals and the other sisters, the politicians on first name terms, the making-do on a tiny budget, heroic operations in a power failure, rains and drought, celebrations. The bubbles pop and evaporate and tail off in a whispered word. I am the only one of her visitors now who asks about Africa, and I ask her only once a year or so. But she still remembers it all.

The tea arrives, and I help her with her large blue plastic mug; the only sound in the room is of her slow sipping. My important schedules fall into irrelevance, just as all hers are long gone. Then the train and the flight from Dublin and my children waiting back home intervene.

I pause to look back through the glass door. I see her veined, delicate hands, once again I see Africa.
Reality bites

Public affairs, Dr Johnson once said, vex no man. What he meant by this, I suppose, is that what really and truly interests and motivates us is our private little world, and that when we pretend to care deeply about politics we deceive both ourselves and others.

Guy de Maupassant has a story making precisely the same point. Dr Massarel is the doctor in the small Normandy town of Canneville, and the leading republican there. The mayor, the Vicomte de Vernetot, is an adherent of Napoleon III.

At the start of the story, which is one of the funniest that I know, two peasants come to consult Dr Massarel. The husband has had varicose veins for seven years, but waits until his wife has them also before consulting the doctor.

During the consultation, the doctor receives news of the Battle of Sedan, the capture of Napoleon, and the proclamation of the Republic. The peasant is explaining his symptoms—“It all started with a feeling of ants running up and down my legs”—but the doctor tells him to shut up, his legs can wait, the Republic has been proclaimed.

Dr Massarel rushes into the town square, where he addresses the townsfolk and the visiting peasants in an exalted fashion. They are completely bemused by this and fail to respond. They think that if the Emperor is imprisoned, someone must have betrayed him.

Dr Massarel is frustrated by their impassivity and decides on a grand gesture. He orders that the white plaster bust of Napoleon in the town hall be overturned the chair with a kick and, putting his foot on the remains of Napoleon’s forehead flew into white dust, but the eyes, the nose and the fine ends of the moustache remained intact.

The doctor then takes further action to impress the crowd. “Exasperated, the doctor overturned the chair with a kick and, putting his foot on the remains of the bust in a triumphal posture, turned towards the astonished crowd and shouted, ‘May all traitors perish thus!'”

But even this fails to arouse the crowd from its apathy, and so Dr Massarel decides to shoot the bust, which has “pointed moustaches that go past the cheek on each side” and is “well-coiffed like a hairdresser’s sign.”

“The bullet made a little black hole in the forehead, like a stain, almost nothing. M Massarel fired a second shot, which made a second hole, then a third, then, without stopping, the last three. Napoleon’s forehead flew into white dust, but the eyes, the nose and the fine ends of the moustache remained intact.”

The doctor then further action to impress the crowd. “Exasperated, the doctor overturned the chair with a kick and, putting his foot on the remains of the bust in a triumphal posture, turned towards the astonished crowd and shouted, ‘May all traitors perish thus!’”

He then retreats to his house and consulting room, where the peasant and his wife are waiting for him. The peasant says, “It all started with a feeling of ants running up and down my legs.”

Does this mean that we should all become political quietists, and deal only with real problems, that is to say formication and the like? The problem is that when we are sucked into politics, or worse still, management, we begin to sound (and perhaps think) like Dr Massarel. This is a dilemma I cannot solve.

Theodore Dalrymple is a writer and retired doctor.
For the full versions of articles in this section see bmj.com

George Douglas Pinker
Surgeon gynaecologist to the Queen

Sir George Pinker succeeded Sir John Peel as surgeon gynaecologist to the Queen in 1973. He later shared with Peel the distinction of also becoming president of the Royal College of Obstetricians and Gynaecologists.

Born in Calcutta and educated in Reading, George Pinker entered St Mary’s Hospital Medical School in 1942. He was active as a student in reviving the musical society which had atrophied during the second world war, and with his fine baritone voice sang one of the leading roles in its first post-war production, the Mikado. Such was the quality of this production that he and two other students were offered professional contracts with the D’Oyly Carte Company. He declined the offer, but his love, knowledge, and understanding of music, particularly opera (and especially Wagner), continued throughout his life. This was reflected in his becoming assistant concert director of Reading Symphony Orchestra and then vice president of the London Choral Society in 1988.

After qualifying George held resident appointments in the department of obstetrics and gynaecology at St Mary’s under three renowned specialists: Alec Bourne (an elegant, well-mannered man of academic brilliance with left wing political views and a very strong social conscience), Douglas Macleod (a highly literate, cultured, and artistic master surgeon), and Leslie Williams (a jovial, blustering obstetrician who was a brilliant didactic teacher). Pinker always paid tribute to this distinguished trio for starting him on his chosen career.

After national service as captain in the Royal Army Medical Corps in Singapore he continued his training in leading hospitals in Oxford and London before obtaining, at the age of 33, a consultant appointment at St Mary’s, Paddington, which included the Samaritan Hospital for Women. Later he accepted an appointment at the Bolingbroke Hospital (1960-70) and the Soho Hospital for Women and King Edward VII Hospital for Officers (1974-89).

As treasurer of the Royal College of Obstetricians and Gynaecologists between 1970 and 1977 he played a key part in creating its charity research arm, initially known as Birthright but later as WellBeing of Women. He was instrumental in persuading Diana, Princess of Wales, to become patron of Birthright, an appointment which electrified its fund raising activities. The post of treasurer was followed by vice president (1980-3), and then president (1987-90). In 1987 Pinker was one of the three English royal college presidents who drew public and government attention to the underfunding of the NHS with a letter to the Times, prompting the Thatcher government to conduct an NHS review and introduce the internal market.

George held his appointment as surgeon gynaecologist to the Queen and the royal household with pride and discretion. He supervised nine royal births, all of them at the Lindo Wing, St Mary’s, rather than at a royal residence. This historic break with tradition illustrated his guiding principle that the welfare and safety of all his patients, royal, private, or NHS, were his non-negotiable priorities. He was appointed a CVO in 1983 and a KCVO in 1990. Pinker had a large private practice. One of his patients organised a 70th birthday celebration for him in 1994 at Grosvenor House in London, which was attended by two queens, two princesses, and one duchess.

He held visiting appointments and was awarded travelling lectureships in Africa and Australia, as well as examining widely both in the United Kingdom and abroad. He was awarded honorary fellowships by the equivalent postgraduate colleges of South Africa, Australia, and the United States. He also coauthored two undergraduate textbooks and served as chief medical officer to BUPA and on the council of the Winston Churchill Trust. He remained immensely loyal to St Mary’s and took his responsibilities as a teaching hospital consultant seriously. A fine teacher, his support and friendship to his colleagues never faltered throughout his career.

George loved sailing, skiing, and fell walking. He was a keen and knowledgeable gardener, as taught by his father, a horticulturist with Sutton’s Seeds for 40 years and head of the bulb and flower department for 25.

Sir George’s final appointment was as president of the Royal Society of Medicine in 1992. By this time symptoms of his long disabling illness were becoming apparent, but he still continued to host meetings and chair committees with his customary charm, diplomacy, and talent for finding a compromise solution when there were marked differences of opinion. His last 10 years were marred by his and his wife Dorothy’s ill health. Despite his own disability, he cared for Dorothy until her death in 2003. Alone, wheelchair bound, and with failing eyesight, he still loved visitors, conversation, gossip over a pub lunch, and, above all, music. He leaves three sons and a daughter.

Alasdair Fraser, Frank Loeffler
Sir George Pinker, surgeon gynaecologist to the Queen, president Royal College of Obstetricians and Gynaecologists (b 1924; q St Mary’s, London, 1947; KCVO, FRCS, FRCSed, FRCOG), died on 29 April 2007 from an acute abdomen.

| 1378 | BMJ | 30 June 2007 | Volume 334 |
Russell John Boyd
Consultant in emergency medicine
Adelaide (b 1965; q Edinburgh 1989; MRCP, FFAEM, FCAEM), took his own life on 9 December 2006. Russell trained in emergency medicine in the northwest of England. As a registrar he was an enthusiastic instructor on life support courses. His calm and patient manner contrasted with the more aggressive and imposing teaching style of some of his contemporaries, so that he could always be relied on to nurture and encourage shy or reticent candidates. Russell had the worst handwriting any of his contemporaries had ever seen, a fact he attributed to a childhood injury. He became a consultant in 2000, and a year later moved from Manchester to Adelaide, where he developed an interest in retrieval medicine and rediscovered his enthusiasm for exercise, taking up triathlons. He leaves a wife, Alison, and two children.

Bernard A Foëx, Simon D Carley

Glyn Ieuan Tegeryn Griffiths
Former general practitioner
Camberwell, south London (b 1923; q Liverpool 1947), died on 25 February 2007 after a fall. Glyn captained the university soccer team and won a junior international cap for Wales in 1947. After qualifying he did his national service in the Royal Air Force, for whom he played football. He became a general practitioner in 1951. He was on the obstetric list for nearly 30 years, with general practice beds at Guy’s, St Thomas’s, and Dulwich Hospitals, and a senior police surgeon to the Metropolitan Police until 1980. After retiring from general practice in 1984 Glyn became ship’s doctor with Epirotiki Lines and Swan Hellenic Cruises and then surgeon chief officer with the Royal Fleet Auxiliary until 1992. He loved travel, his garden, and antique clocks and was a fellow of the Zoological Society. He leaves a wife, Barbara; three children; and five grandchildren.

Mary Anne Griffiths, Barbara Griffiths

Lawrence Gordon Jubb
Former general practitioner
Govan (b 1916; q Glasgow 1939), died from a stroke on 27 February 2007. Lawrence Jubb was an inner city general practitioner in Govan from 1948 until his retirement in 1981. While serving in the Royal Army Medical Corps in Palestine, Ethiopia, and North Africa, he developed an interest in anaesthetics that he pursued throughout his career. He preferred patients to politics; he always visited patients he had admitted in hospital. He enjoyed a long and active retirement. His diverse interests included palaeontology at the Hunterian Museum, painting, lapidary, stained glass, and a lifelong love of classical music. He created glass pictures and was preparing for a one-man exhibition this year. Predeceased by his wife, Jessie, in 1996, he leaves three sons and seven grandchildren.

Ronald Jubb

Thomas Edwin Moody
Former general practitioner
Stockton on Tees (b 1916; q Belfast 1939), d 8 March 2007. On qualifying Edwin joined the division. Married to Hilda for over 60 years, he leaves five children and 14 grandchildren.

Thomas Laurence Moody
John Kirkpatrick

Robert James Sanderson
Consultant otolaryngologist
Edinburgh and Livingston (b 1960; q Manchester 1984; FRCS, FRCS (ORL-HNS)), died from intracranial lymphoma on 13 December 2006. Robert Sanderson (“Rob”) specialised in treating ear, nose, and throat malignancies. He and his brother Paul were the first identical twins to pass the FRCS in general surgery together. Rob did his specialist training in Edinburgh with Arnold Maran, followed by a fellowship in head and neck surgery in Rotterdam under Paul Knegt. There he learnt Dutch and met his wife. Rob loved to teach, was active in training, lectured frequently, was lead clinician in the Scottish head and neck audit, was regularly a guest speaker at national and international meetings, and wrote and cowrote several chapters in books. He leaves a wife, Christine, and three young children.

Gillian MacDougall, David Sim, Paul Sanderson, Christine Tolsma

William Todd
Former Church of Scotland medical missionary; chief medical officer, Nchanga Consolidated Copper Mines, Kabwe, Zambia; general practitioner Linwood (b 1924; q Glasgow 1947), d 9 November 2006. In 1948 William Todd (“Bill”) came as a medical missionary to Jalna, India. In 1958 he became a general practitioner in the Gorbals in Glasgow. Returning in 1965 to Africa, where he had been born, he performed major surgery in the Zambian Copperbelt. From 1976 until retirement he was again a general practitioner in Scotland. A church elder for 40 years, Bill received a bravery award from the Humane Society in his 60s, when he rescued a man who was being swept to his death in the flooded waters of the Gryffe. Predeceased by his wife, Muriel, he leaves three children.

John Todd

Philippa Mary Bruce White
Consultant microbiologist
Norwich University Hospital (b 1953; q University College, London, 1977; MSc, FRCPath, MBA), died from breast cancer on 23 December 2006. In 1980 Philippa Mary Bruce White joined the Public Health Laboratory Service (PHLS) as a registrar in Birmingham. She later became associate specialist to the Virus Reference Laboratory, Colindale, and was appointed consultant microbiologist in Norwich in 1988. Within a year Philippa became laboratory director and then in 1996 group director of PHLS East, pioneering the development of a network of microbiology departments in the east of England. She also taught at the University of East Anglia. She loved animals and was fluent in French. She leaves a partner, Tony Hegarty.

Margaret Sillis, Helen Williams, Judith Richards

BMJ | 30 JUNE 2007 | VOLUME 334

1379
A BMI reader is writing a biography of Charles Thomas Haden (1786-1824), a London doctor who was greatly admired by Jane Austen, and is looking for information on the location of Haden’s private and professional papers, letters, and journals, and the papers of his wife, Emma Harrison. Haden was a surgeon at the Chelsea and Brompton Dispensary, vice president of the Associated Apothecaries and Surgeon-Apothecaries, part-editor of the Medical Intelligencer, and translator of Francois Magendie’s Formulary (1823). If you can help, please contact Brian Southam on brian_southam@hotmail.com.

Is there a connection between exposure to rubbish in cities and diarrhoea in young children? Unsurprisingly, a longitudinal study carried out in Brazil suggests there is (Transactions of the Royal Society of Tropical Medicine and Hygiene 2007;101:722-9). An index of “rubbish in the street” and uncontained rubbish within the home were both associated with diarrhoea. Less significant associations were the quality of water supply, hygiene and cleanliness near the house, the number of people living together, drainage problems, and the age of the child.

A seven year prospective birth cohort study of nearly 4000 children delivered at term found that lower birth weight was associated with a transiently increased risk of respiratory symptoms. This risk was further increased if children were also exposed to environmental tobacco smoke. This effect of birth weight increased up to the age of 7 years but was no longer significant at the age of 12. Interestingly, birth weight and a diagnosis of asthma were not related (American Journal of Respiratory and Critical Care Medicine 2007;175:1078-85).

The prevalence of use of methylphenidate (Ritalin) at any time between 1994 and 2000 in Canadian children with attention-deficit/hyperactivity disorder was almost twice as high in children whose parents have been through a divorce compared with those whose parents were still together (6.1% v 3.3%) (CMAJ 2007;176:1711-4). Taking the age and sex of the children and the age of the mother out of the equation, drug use was significantly higher among children whose parents subsequently divorced (odds ratio 1.82 (95% CI 1.01 to 3.33)). The question is what causes what?

Several observational studies have indicated that taking calcium and vitamin D supplements reduces the risk of common cancers. Now an interventional, double blind trial of supplements taken by postmenopausal women over four years confirms the findings. The incidence of cancer was significantly lower in the group taking supplements compared with the placebo group (American Journal of Clinical Nutrition 2007;85:1586-91).

A survey of US patients receiving treatment for infertility found about half of those who replied would willingly donate their unused embryos for stem cell research rather than have them destroyed or donated to another infertile couple (Science 2007 doi: 10.1126/science.1145067). US legislation still bans stem cell research, but most patients would willingly donate their unused embryos for stem cell research rather than have them destroyed or donated to another infertile couple or dependency.

What happens to people who have experienced atrial fibrillation at some point? A 30 year follow-up suggests that about a quarter progress to permanent atrial fibrillation, but survival in general is similar to age and sex matched patients without atrial fibrillation (Circulation 2007;115:3050-6). The risk for stroke or transient ischaemic attack was also similar to that for the matched control group during the first 25 years, but thereafter the risk increased.

Carers of elderly adults were randomly assigned to participate in three types of writing sessions: expressive writing, time management, and history writing. Contrary to expectations, only those in the time management group (who wrote objectively about how they spent their time) experienced significant improvements in their mental and physical health; they were also more likely to report that they found the exercise valuable than were the participants in the other two writing groups (Gerontologist 2007;47:296-306).

A prospective comparison of conventional and laparoscopic total hip arthroplasty—both performed via a posterior incision—comes out in favour of the minimally invasive approach (Journal of Bone and Joint Surgery 2007;89:1153-60). With 30 patients in each group, the keyhole group achieved better early pain control, went home earlier, and had less need of walking devices. But after hospital discharge both groups had similar levels of pain and function.

Commenting on a review of sex and the nose published in the Journal of the Royal Society of Medicine, which presents evidence that humans use odour to influence mate selection, the editor of the journal says, “for men in relationships this paper helps us understand one of the fundamental mysteries of the universe: why the hell did our partners choose us in the first place?” (2007;100:251). For men who are less successful at wooing their partner of choice, he helpfully suggests, “try someone else, or find yourself a new deodorant.”

It’s not just parenting that counts when it comes to producing well adjusted adults; the relationships children have with their brothers and sisters also matter. A 30 year study reports that poor sibling relationships during childhood may be an important and specific predictor of major depression in adulthood, in addition to a family history of depression (American Journal of Psychiatry 2007;164:949-54). Failing to get on as children did not predict later alcohol misuse or dependency.