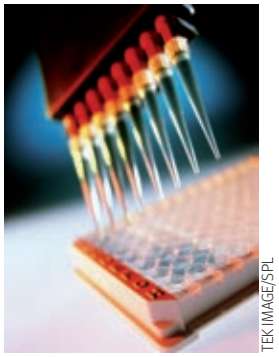
Reducing the length of time between HIV infection and diagnosis

Targeting high risk groups should remain the priority



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ANALYSIS, pp 1352, 1354

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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.[1 2] 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.[3] This goal allows a range of measures of success beyond a CD4 count below 200×10^6/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."[2] 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.[4]

HIV is one of the most stigmatised diseases.[5] 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.[1 2] However, studies in the UK show that health professionals in non-HIV specialist settings discriminate against people with HIV.[5 6] 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,[2] 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[7]—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.[8] 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.[9]

In the UK in 2005, 20 100 people were assumed to have undiagnosed HIV.[8] 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.[10] 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.[11]

Since the publication of the national strategy for sexual health and HIV,[12] 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%.[8] 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)[13 14] and how long people have to wait for results.[15]

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.

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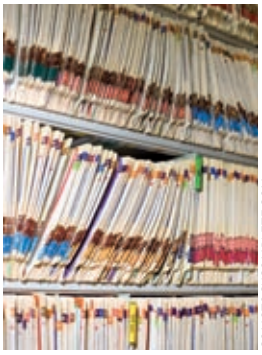
Ethics of collecting and using healthcare data

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



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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,[1-3] and with epidemiological research based on population-wide databases, such as the United Kingdom's new National Health Service programme,[4] 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.[2 3] 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.[2 5 6] 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.[3 6 7]

Data protection laws make the resolution of this problem urgent. Quality assurance may be stopped,[2 8] unethical activities may occur,[8 9] 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.[10]

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.[11] 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

Questions to ask of any systematic data collection process in health care

Design
Will the method answer the question being asked?

Process
How much will each participant be informed about the study?
Will each participant be able to choose whether or not to participate?
Will the method of recruiting participants be fair?

Cost
What organisational resources will the project use?
What extra burden will be imposed upon the participant(s)?
What additional risks will the participant(s) face?

Benefit
What benefit might accrue to the participant(s)?
What benefit might accrue to society?

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.[12]

Ethically difficult situations that require independent help will still arise. Existing ethical review committees could provide independent advice,[3] 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.[2] 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.

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Lactose intolerance

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

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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

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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 excoriations 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.[4] 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 preclude 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.[5] It may help to divide daily milk intake into several small portions and to take it with other foods. Yoghurt, curds, and cheeses are better tolerated, because lactose 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.[6] 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.[7] 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.[8] 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.[9] 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.[10] 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.[11 12]

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.

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Performance measurement and equity

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

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RESEARCH, p 1357

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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.[1] So too are inequities in access, quality, and outcomes linked to gender, ethnic origin, and socioeconomic status.[2] 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.[3] 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.[4,5] 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.[6] However, optimism about potential benefits is tempered by growing concerns about potential harms.[7]

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.

Socially 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.[8] Equity is a major dimension of healthcare quality and a key attribute of high performing health systems,[9] 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.[10] 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.[11] 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.[12] 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 (www.powerstudy.ca).

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.[13,14] 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.

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Involving patients in the *BMJ*

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

L WOODS

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The *BMJ* is a journal for doctors. Its mission is to 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.[1 2] 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.[3]

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.[4 5] 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.