Difficulties in giving fully informed consent

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Ten ways to improve information technology in the NHS

Any change in information technology in general practice requires extensive piloting

Editor—I disagree with Majeed et al’s contention that better information technology support for practices requires locating patients’ records on central servers. Good support for practice based servers may be a better choice.

Running a primary care trust’s records on a single server is a high risk strategy that makes the entire functioning of primary care in a locality vulnerable to any problem with the central server and makes a practice’s access to its records vulnerable to problems with its telecommunications links.

Access to information on patients’ records must be instantaneous. With very short consultation times we cannot afford even brief delays, which would result in practitioners not bothering to access as much information from records as they otherwise might. Any proposed system based on a central server should be piloted for at least a year before committing to a wider rollout.

Patients’ records are currently deteriorating with manual re-entry (usually by staff who are not medically qualified) of important details from the vast printouts handed on by paperless practices. We urgently need not only a transferable structure for electronic records made by general practitioners but also a mandated standard filing structure for scanned correspondence. Every paperless practice is currently inventing its own, which will have dire consequences for the future functionality of electronically transferred correspondence files.

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Competing interests: None declared.


Editors—The interest in Majeed et al’s article on ten ways to improve NHS information technology highlights the fundamental mismatch of perspectives between management and doctors.

An effective solution can work only if the approach is patient centred. This conceptual naivety is striking when doctors try to tell the government how to do its job. Of course the government can’t do much better. It has pumped hundreds of millions of pounds into the NHS information technology system over the past 10 years, and what has it to show for it?

Every point in the article was thought of 15 years ago. The problem is not a shortage of needs but one of delivery. It is not about need but implementation. The government has a slightly different agenda from primary care doctors, and secondary care needs differ once again.

The government has three bottom lines: trolley times in accident and emergency wards, waiting times, and balancing its books. Any information technology system must focus on these remits. Hopefully, these bottom lines are patient focused. However, whether your aged mother is lying on a trolley or a trolley without wheels (a bed) in an accident and emergency department is hardly going to change when the NHS net becomes efficient.

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Current situation in the United Kingdom need not be so

Editor—Majeed et al detailed a wish list for information technology in the NHS. For the past 10 years I have worked in a district general hospital in New Zealand. Like that in Britain the country’s public health system is under constant pressure from inadequate funding, chronic understaffing, and escalating demands from patients, politicians, and others. Unlike Britain, New Zealand has a very small population that generates minus-cule revenues in global terms. Most indices of health and wealth have declined relentlessly, in absolute and relative terms, for decades.

Despite this my hospital, and many others, invested in a modern information technology system. For years letters have been dictated over the telephone on to a digital system for storage or typing. All correspondence, laboratory results, clinical photographs, patients’ details, and administrative records are accessible in seconds from any terminal. Radiology and histopathology images are incorporated into the system.

Coming to work in the United Kingdom was like returning to the technology used in New Zealand over 10 years ago. Investment has been little, and staff have received almost no training in the use of even the most basic

Notes


2 Murray Flett.


Notes


2 Murray Flett.
information technology. Facilities that would not be put up with for one moment at home are tolerated and endured at work with a dogged carry on.

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Primary care doctors need to become aware of training opportunities

EDITOR—Majeed et al call for additional training to allow all members of the primary healthcare team to take advantage of resources such as the National Electronic Library for Health.1 In our experience, a wide range of information handling skills exists among this group, as does a general lack of awareness of what electronic information resources are available to them.

We recently appointed a primary care information skills development officer to enhance local awareness of electronic and other information resources and to provide training to any member of primary care staff in Oxfordshire in the use of these resources. The post is funded by Oxfordshire’s local implementation strategy team. There have been many similar appoint- ments in recent years throughout the United Kingdom. We would urge all primary care practitioners to contact their nearest health- care library to find out what local training opportunities are available.

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Computers in the workplace are of great value

EDITOR—Melichar and Bland discussed doctor and computer.1 Working at the Mayo Clinic I have come to appreciate the value of access to high grade information technol- ogy. Mayo supports a free internet service provider to all employees. A 24 hour service is available to help people at work or at home. The “microcomputer education serv- ice” offers classes on how to get the most out of the software. Every on-call room has computer access to patients’ electronic records and all data pertaining to patients’ care. All terminals have access to the internet and email.

The philosophy of this institution is that investment in information technology results in the staff feeling supported and thus more efficient. The lack of investment in infor- mation technology in the United Kingdom is a major hindrance to progress. The “short termism” in health politics precludes the abil- ity to improve efficiency in the workplace. Information technology should be a priority for spending in the NHS.

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Competing interests: None declared.

Closing the digital divide

Reality may not be so rosy

EDITOR—Smith applauds the progress made in providing access to the internet in the developing world.1 Unfortunately the reality on the ground may not be as rosy.

I have just completed two years in a major sub-Saharan African university that was in the first phase of HINARI access. Having been initially starved of information while there I rushed to gain access. Unfortu- nately I was directed to the websites of two other international projects that were also providing free access to research materials over the internet.

I found poorly presented sites with complex addresses and passwords, and with limited access to full text journals. I contacted the projects repeatedly over the following months from my local internet café, trying to get better materials, but finally gave up, frustrated. It was only on my return to the United Kingdom that I discovered that I had been initially starved of information while there. Unfortunately I was directed to the websites of two other international projects that were also providing free access to research materials over the internet.

I found poorly presented sites with complex addresses and passwords, and with limited access to full text journals. I contacted the projects repeatedly over the following months from my local internet café, trying to get better materials, but finally gave up, frustrated. It was only on my return to the United Kingdom that I discovered that I had been initially starved of information while there. Unfortunately I was directed to the websites of two other international projects that were also providing free access to research materials over the internet. Can we ensure that access to HINARI is available to those who need it? If I—as someone who was in the university, computer literate, and keen to access journals—failed, then there is little hope for the rural majority with limited computer skills.

Communication in countries must be improved through training programmes and publicity. But it is also the responsibility of international projects participating in information supply to the developing world to direct casual searchers like myself to good quality central portals like HINARI rather than to their own poorer versions. All too often good resources can be confounded by interagency competitiveness. To ensure that the HINARI address is spread as widely as possible, all need to focus on this major portal so that the users at the sharp end do not receive confused messages.

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Folate and risk of cardiovascular disease

Study results were misinterpreted

EDITOR—Huang et al conclude that their cohort study on serum folate and coronary heart disease provides evidence against the view that folic acid prevents coronary heart disease.1 We disagree and believe they have misinterpreted their results.

A meta-analysis of studies on homocysteine and cardiovascular disease, supported by others,2–4 together with randomised trial evidence on folic acid dose and serum homocysteine reduction, shows that the maximal homocysteine lowering effect of folic acid occurs at a dose of about 0.8 mg/day (which increases serum folate by 20 μg/l).3 This homocysteine reduction lowers the risk of coronary heart disease by about 16%. The difference in average serum folate between the highest and the lowest folate group in the cohort study of Huang et

Financial and technical obstacles must be eliminated

EDITOR—Like Smith, I think that HINARI is an excellent idea and one that has great potential to improve health care in developed countries.1 However, I had three concerns about the current programme.

Firstly, when I looked at the list of eligible countries, I noted that three south Asian countries (Pakistan, India, Bangladesh) were not included, even though all three countries would seem ideal candidates for the HINARI programme (they have a combined population of over 1000 million people and a large pool of English speaking doctors). I wondered therefore why they were excluded. Of course, their omission from the list may simply be a clerical error, but if this is the case, it needs to be corrected.

Secondly, the current uptake of HINARI seems low given its potential. Smith said that 438 institutions in 68 countries eligible for free access have signed up thus far. This gives an average of six or seven institutions per country, which means that HINARI’s current penetration is still very low. Hence, obstacles to the greater uptake of HINARI need to be identified and overcome.

Thirdly, the $1000 fee payable for access to journals may be affordable by large insti- tutions but not by community health centres or doctors working in singlehanded or small group practices. We therefore need to ensure that financial obstacles do not hinder the uptake of HINARI.

HINARI has great potential to reduce the digital divide, but we need to ensure that financial and technical obstacles do not hinder its uptake.

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Competing interests: None declared.

1 Smith R. Closing the digital divide. BMJ 2003;326:238. (1 February)

1 Smith R. Closing the digital divide. BMJ 2003;326:238. (1 February)
al was about 7 µg/L, since the median of the highest folate group was about 8 µg/L (the 93rd centile was stated as 9 µg/L, so the 85th centile must have been less than this) and the median in the lowest folate group was about 1 µg/L (stated as 3 µg/L).

Since a 20 mg/L higher serum folate is associated with a 10% higher risk of coronary heart disease the 7 µg/L difference will be associated with a 5% higher risk, a relative risk of 1.05 (1.16%) consistent with the 1.10 (men) and 1.14 (women) in their study. These results weigh in favour, not against, the view that folic acid reduces the risk of coronary heart disease. The narrow range of serum folate values in their cohort study limits its ability to show a significant effect.

Table 4 in the paper confirms the link between low serum folate and increased risk of coronary heart disease. Hung et al present data from six other cohort studies. Each shows a higher risk of coronary heart disease in the lowest folate group compared with the highest. This observation alone is highly significant. The probability that all seven studies have estimates above 1.0 by chance is less than 1 in 128, a P value of 0.008. The cumulative evidence is irrefutable.

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Authors’ reply

Enròrr—Wald et al oversimplify the relation between serum folate concentration and coronary heart disease, and they have ignored our results for red cell folate, a more reliable indicator of long term folic acid intake than serum folate. The reference interval for red cell folate in our cohort was 114-608 µg/L in men and 101-604 µg/L in women, indicating a wide range of folate values consonant to that reported in other general populations. The power of our study to detect a relative risk of 1.2 associated with a change of one standard deviation (150 µg/L for red cell folate) was about 90% for death from cardiovascular disease and 70% for death from coronary heart disease.

Wald et al state that serum folate needs to increase by 20 µg/L to lower the risk of coronary heart disease by 10% on the premise of lowering homocysteine concentrations by 3 µmol/L. However, the Framingham heart study showed a difference > 5 µmol/L in mean homocysteine concentrations across the population within a comparatively narrow range of serum folate values from 2 to 8 µg/L. We found similar results in a general population.

Furthermore, the effect of raising folate concentration can be underestimated by the reduction in mean homocysteine concentration. For example, a population increase in serum folate from 4.6 to 10.0 µg/L decreased the prevalence of high homocysteine (> 13 µmol/L) from 18.7% to 9.8% but reduced mean homocysteine concentration by only 0.7 µmol/L.

Folates should not be assumed to prevent coronary heart disease only through lowering homocysteine concentration as other mechanisms may exist.1 Hence we did not argue against public health efforts to raise folate consumption in the general population by appropriate dietary measures. We argued against the routine use of vitamin supplements to lower homocysteine concentrations in the general population until their benefit is proved by controlled clinical trials.

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Chronic cough

Article is not consistent with WHO initiative on rhinitis and asthma

Editor—The discussion on rhinitis in the article on chronic cough in the 10-minute consultation series seems inconsistent with the World Health Organization’s recent initiative on allergic rhinitis and its impact on asthma.1

The classification of rhinitis used (“ perennial” and “ seasonal”) has been superseded by the subdivisions “ intermittent” and “ persistent” rhinitis, graded “ mild,” “ moderate,” or “ severe,” which is believed to have advantages in understanding the condition and in guiding treatment. The initiative lists pharmacological options as oral or local decongestants, oral or local antihistamines, intranasal corticosteroids, and local anti-cholinergics, with other options including systemic corticosteroids, local chromones and antileucotrienes.

In mild intermittent rhinitis, antihistamines are recommended as first line treatment, with the addition of nasal corticosteroids or chromones for moderate to severe intermittent disease. Nasal steroids are recommended for earlier use in persistent disease, with the addition of ipratropium if rhinorrhoea is prominent. This algorithm is different from that presented in the article.

The article is also not clear on what is meant by “ non-allergic rhinitis” or how general practitioners are to differentiate it from allergic rhinitis other than by skin prick or radioallergosorbent testing to aeroallergens. These investigations are commonly available in primary care, but current evidence is lacking on the clinical or cost effectiveness of routine testing. No reference is made to justify the debatable first line use of ipratropium in non-allergic rhinitis.

Although the article makes useful points on the differential diagnosis and the management of patients with chronic cough, consistent messages need to be given on important and common conditions such as rhinitis.

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Don’t forget pertussis...

Editor—The 10-minute consultation on chronic cough did not mention pertussis (whooping cough), a common yet under recognised infection in adults.1 We have become increasingly aware of the clinical significance of pertussis in our general practice population, confirming infection in numerous patients, including previously vaccinated children, middle aged adults, and elderly patients.2 The recent addition of pertussis vaccine to the United Kingdom preschool booster acknowledged the endemic nature of this problem.

Specifically, patients have a tracheal cough that is worse at night and on exercise. Vomiting with coughing is frequent, and an audible whoop may develop. Symptoms tend to last for three months, and the characteristic cough may return with subsequent respiratory infections.Confirmation of pertussis infection is by culture from nasal swabs in cases presenting early or by serological investigation.

When the diagnosis is suspected, patients should be investigated appropriately. The respiratory and systemic infection
laboratory of the Central Public Health Laboratory will undertake serological investigation of patients with a persistent cough (exceeding three weeks). The chief advantage in making the diagnosis is in avoiding confusion with other conditions, such as asthma. This is a concern because a therapeutic trial of asthma drugs may coincide with natural resolution of pertussis infection. Recognition of pertussis can also help to ensure infected persons minimise their contact with young prevaccinated babies.

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...tuberculosis ...

Editor—Currie et al summarise the issues and differential diagnosis of patients presenting in primary care with a chronic cough. They suggest arranging chest radiography in smokers and in people at risk of tuberculosis or immunosuppression, as well as in non-smokers if the diagnosis is not clear.

An outbreak of tuberculosis at a school in London in 2001 highlights how doctors must be ever vigilant of tuberculosis and not just in people at risk of acquiring the disease. This outbreak led to a total of 251 adults and children needing screening. A total of 12 more cases of tuberculosis disease and 55 cases of infection were discovered; six of the cases of tuberculosis disease were children.

The outbreak investigation found that neither the index case nor any of those who were found to have disease and infection fell into any of the risk categories. The index case was seen by a series of primary care doctors, then in secondary care, as an NHS patient and in the private sector, and yet tuberculosis was not considered. Even chest radiology for atypical shoulder pain reported the lungs to be clear; this was later discovered not to be the case. Tuberculosis was diagnosed 18 months after the initial contact and only when the index case had been admitted to an accident and emergency department after collapsing while away from home.

Cotulation skills, thorough history taking, and continuity of care are necessary. Rapid access to any primary care professional in the practice may reduce the common thread of thought that helps to identify the unusual presentation of a common problem.

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...and tropical pulmonary eosinophilia

Editor—Tropical pulmonary eosinophilia is one of the commonest causes of chronic cough in tropical regions where filariasis is endemic. It may occur after infection with all types of nematodes causing filariasis. The disease results from a hypersensitivity reaction to the microfilariae in the capillaries of the alveoli.1 It is common among non-immune visitors to endemic areas.

The disease is characterised by parasymmetrical cough occurring especially during the night, wheezing, malaise, sometimes low grade fever, and hypereosinophilia. The absence of microfilariae from the blood and raised concentrations of serum total immunoglobulin E > 1000 IU/ml support the diagnosis.

Early diagnosis and treatment is necessary as untreated disease may result in long term sequelae such as pulmonary fibrosis or chronic bronchitis with respiratory failure.1 The condition used to be seen only in people living in the tropics, but increased travelling has made it more common in the West. Since the clinical symptoms overlap with those of many other conditions that cause chronic cough—such as asthma, sinusitis, etc—doctors need to be aware of the possibility of tropical pulmonary eosinophilia in a patient who presents with a chronic cough.

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Leishmaniasis also occurs in Mediterranean countries

Editor—The clinical review on leishmaniasis by Davies et al focuses on new developments in developing countries, where the disease is endemic.1 However, leishmaniasis also occurs in all Mediterranean areas, although the incidence of the disease fell sharply after the intensive spraying with antimalarial insecticide (DDT, dichlorodiphenyltrichloroethane) in the 1950s to reclaim land and improve housing conditions. Before 1948 our department used to see an average of 143 cases of visceral leishmaniasis yearly (range 20-302); subsequently the number fell to 10 (range 2-22).

People at risk are not only those living in Mediterranean countries but also holiday-makers. The incubation time may be as long as two years, so the typical symptoms (fever, anaemia, spleen enlargement) may arise long after the return home, and it may be difficult to reach the correct diagnosis.

All doctors should strongly suspect leishmaniasis when its typical symptoms arise in someone who has spent some time where the disease is endemic, including Mediterranean countries. However, even Sicilian family doctors rarely think of leishmaniasis and often refer patients to our department with a clinical suspicion of malignancy.

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Medical experts and the criminal courts

Meaningful audit could be difficult to attain

Editor—Although I agree with Milroy, I think it unfortunate that he did not extend his editorial to propose a system for the auditing and assessment of quality in medicolegal work.1 Experience shows that meaningful audit could be very difficult to attain for many reasons that include the following:

The first is the legal system. The adversarial system is simply one of winning and not one of finding the truth. This encourages the use of “hired guns” and brings pressure on experts from both sides to provide “favourable” reports in the interests of maintaining client satisfaction and obtaining further medicolegal work.

The second is the absence of evidence based forensic medicine. Properly conducted research in the field has been comparatively limited and many of the forensic “facts” are neither supported by nor based on controlled research findings but on published personal views.

The third is personalities and titles. Personality conflicts and favouritisms can interfere in the objective assessment of performance and the establishment of a list of accredited “experts.” Titles are a problem as professorial and associate professorial appointments are not always indicators of either knowledge or competence, although they are often viewed as such, particularly in the courts.

The fourth is representation. People who provide medicolegal services are associated with a wide variety of learned societies and colleges. Most do not have effective audit systems in place, and even if they did, no uniform standard exists across all fields.

The last is assessment of court performance. Court presentation is an important aspect for any medicolegal practitioner but can this be objectively and inexpensively assessed?

Audit and quality assurance programmes are certainly necessary and are
Involving community may be way forward post-Shipman

Editor—Baker et al monitored mortality in general practice after Shipman.1 A statistical monitoring process with high enough sensitivity to detect murder would almost certainly give many false positive signals. This could cause severe damage both to practitioners and to their relationships with their patients. An alternative monitoring process with high enough specificity to avoid false positive signals may take so long to signal that many preventable deaths could occur. A practitioner bent on deliberate murder would almost certainly be expert at gaming any such monitoring process. Requiring groups of practitioners to review the deaths in their practices at regular intervals with a view to improving the quality of patient care is an excellent idea, but it is difficult to see how this would deter a murderer.

It is essential for dealing with substantial performance that the underlying system is first analysed carefully and fixed. Judgmental monitoring without that first essential step is likely to generate an environment in which “proving that you comply with the benchmark,” if necessary by employing gaming, becomes the norm at the expense of using data to learn how to do better. Such an environment guarantees poor morale and mediocre performance.

When confronted with problems such as those of Shipman, the bureaucratic response is often centralised, unwieldy, damaging to trust, and costly. Often a solution that is more effective, capable of enhancing trust, and much less costly can be found—for example, by involving the community in the process. Communities that support a general practitioner will usually have a lawyer, accountant, or justice of the peace. With suitable training such people could be involved in the death certification process. There may be better ways of involving the community, but this idea illustrates the problem.

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Cleft lip and palate services still need to be improved

Editor—The report of the Clinical Standards Advisory Group in 1998 was highly critical of the care for people with cleft lips and palates in the United Kingdom.2 Fundamental recommendations included reducing the 57 cleft units to between eight and 12. This represented roughly one cleft centre for each of the areas covered by the old regional health authorities. The report was accepted in full by the Department of Health and endorsed by every major professional association concerned with cleft care.

Cleft lip and palate services were identified as a national priority,3 and a commissioning framework was produced to ensure that the recommendations were implemented. NHS trusts and health authorities were instructed to review their services to ensure that these were consistent with this framework.4 The service, directed by an implementation group,5 was to be in place no later than 1 April 2000. Regrettably, this has not happened, and although some centres have now been established, several regions have not even reached the stage of public consultation. In some areas trusts, managers, and clinicians are at loggerheads, with no resolution in sight.

It is astonishing that five years after the clinical standards advisory group’s report was published we are still some distance from implementing its recommendations. The delay to service has resulted in considerable frustration and anxiety to clinicians and patients alike. Furthermore, recruitment to the service may be difficult to achieve as able clinicians may decide not to enter a specialty with such an uncertain future.

The Department of Health must take control and fulfil the promises made when the report was accepted.

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2 NHS Executive. CSAG report on cleft lip and/or palate services. Health Service Circular 1998/002, 23 February. www.infodoh.gov.uk/docs/cnotes/12401/b4f76d7m02062536004b48df84a4e4612b00256ad004b4855/3FLRE/3BSC.PDF (accessed 16 Apr 2003).

Encouraging insensitivity in doctors is not an option

Editor—There may be a sense in which being a caring doctor may be bad for you, as suggested by Sweet in her report of a study into the psychological health of students from University of Sydney medical programme.1 With the changes in medical education over recent years, many medical schools now have similar aims to this programme, which are to encourage students to become caring and uncaring and being defensive about caring too much.2 Doctors do have to cope with emotionally difficult situations.

Doctors feel exposed in modern health systems,3 They may no longer have their traditional defences to fall back on. The
private, individual contractual relationship with patients may need regulating, and state and social insurance systems create responsibilities for employers. Personal vulnerabilities may be difficult to negotiate openly and honestly with patients. Tolerating uncertainty may be anxiety provoking. More research is required to investigate such personal and professional pressures and their impact.

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1 Sweet M. Being a caring doctor may be bad for you. BMJ 2003; 326:355. (15 February.)
3 Bundy C. Being a caring doctor is not an option. Electronic response to ‘Being a caring doctor may be bad for you. bmj.com 2003. bmj.com/cgi/eletters/326/7385/355/ a=29644 (accessed 15 Apr 2003).

Senior medical staff need to be included in severe asthma

Editor—Rees has drawn attention to the importance and usefulness of the new asthma guidelines, but he questioned the necessity of the authors’ view that senior medical staff should be consulted in a situation where there is clear evidence of benefit (use of intravenous magnesium for severe asthma).¹

As a member of the group developing guidelines for the management of acute asthma for the British Thoracic Society-Scottish Intercollegiate Network, I would like to clarify the reason for including this advice in the guidelines. A weakness of the previous guidelines from the British Thoracic Society was the absence of clear advice concerning the involvement of senior staff in the care of patients at high risk. It is common for junior staff to manage severely ill patients and to administer treatments such as aminophylline, which could cause serious side effects without discussing the patient with senior staff.

Intravenous magnesium has been shown to be beneficial and safe in the management of severe asthma. The guidelines recommend that it should be given to patients with life threatening asthma, near fatal asthma, or patients with acute severe asthma whose condition has not responded well to initial treatment. The guideline development group thought that it was important to involve senior medical staff (or intensive care staff) in the care of this small group of high risk patients. The use of intravenous magnesium was seen as a useful trigger to identify these high risk patients or non-responding patients, who clearly require discussion with senior medical staff.

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Competing interests: BRO D is a member of the BTS-SIGN Guideline Development Group for Management of Acute Asthma.

1 Rees PJ. New guidelines on the management of asthma. BMJ 2003;326:546-7. (15 February)

Difficulties in giving fully informed consent

Editor—Willson et al report that most patients would prefer the opportunity to provide consent before anonymised information from their electronic medical records was used for research.² They point out there are major logistical challenges to obtaining such informed consent, especially in primary care, where ethical concerns prohibit researchers from contacting patients directly.³

Gaining informed consent from each individual in a research study including thousands of patients may fall to general practitioners and practice staff, who already have a heavy workload. The additional resource and financial costs would be considerable. General practitioners are unlikely to agree to do this. Thus primary care research using anonymised electronic data may grind to a halt and one of the advantages of electronic patient records may be lost.

Another difficulty is giving people all the relevant information about a complex issue. The participants in the study seem not to have been given information about the costs of obtaining their consent or the possible consequence of the research being discontinued. Would their responses have been the same if they had been aware of the wider implications? Many patients may not want time and resources to be spent in this way and may also agree with the duty of social responsibility.⁴ Individual informed consent might sometimes be inappropriate.⁵

In New Zealand patients are assumed to have given consent if they are registered with practices affiliated with the computer research network of the Royal New Zealand College of General Practitioners.⁶ These practices put notices in their offices, stating that information from a patient’s consultation, investigation, or referral may be used for research once it is stripped of identifying data.

Other solutions are needed that respect patient autonomy without stifling primary care research. Finding ways of improving public knowledge about the research process when using anonymised data is also required.

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Parents are not homogeneous

Editor—Young et al offer an important insight into the rub between parental desires to protect their offspring from unpleasant news while at the same time recognising their child’s autonomy.¹ However, the paper falls short in two respects.

Firstly, although Young et al say that they did not address the influence of sex, this factor cannot be simply discounted without explanation. Upholding the argument that qualitative data need analysis by sex is the recognition of the existence of women’s health movements and policies and of literature pertaining to men’s health on the basis of salient social theories. Young et al needed to recognise that the discourse of male children and young adults did not or did, in some way, differ from those of their female counterparts.

Secondly, the voices of the mothers and fathers were aggregated into a single factor, that of “the parent.” Although not uncommon in family research, this approach to analysing the data assumes that male and female parents or guardians have the same relationship with their children.

This is contrary to literature exploring relations between the sexes in families. One parent may have a closer understanding of the information needs of their child in times of serious illness. Adding to the call for a disaggregation of data relating to parental discourse is an understanding that mothers tend to be the nexus between their family and health professionals. Therefore women are more likely to be the brokers of health information and the key decision makers as to what information is selectively leaked to family members. Men are more likely to concur with their spouse’s or partner’s opinion because they are perceived to be better informed on health and family matters. A verbal account of interparental discussions as to why health information should be withheld would be a valuable prelude to Young et al’s work as it stands.

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