Letters

Consent to the publication of patient information

Incompetent patients may pose a problem

EDITOR—The *BMJ* ethics committee's revised policy on consent to the publication of patient information is laudable,[1] but an important matter remains overlooked: publishing cases involving incompetent patients. Much can be learnt from these cases; be it highlighting clinical difficulties or drawing attention to neglected moral issues. But the guidelines as written may make it impossible to publish them.

Imagine I wished to publish a case involving a traceable adult with learning disability who had requested genetic counselling. Turning to the guidelines, I would be required to obtain her consent before publication. However, obtaining written informed consent from adults with questionable competence could be difficult or exploitative, as they may lack the capacity to understand the implications of consent to publication. Furthermore, the exceptions listed under point 3 do not apply. Merely anonymising her information would be ethically problematic, as could drafting a fictional case "inspired" by the clinical encounter. Until the mental capacity bill becomes law, no one can provide consent on her behalf. How should we balance the value gained from publishing these cases with respecting the interests of the people involved?

Rogers and Draper have already addressed this issue in the context of medical ethics research and teaching.[2] They argue that using cases with practical obstacles to obtaining consent can often be justified by an appeal to public interest arguments, such as the public's right to know what clinical and ethical dilemmas doctors face.

Although more discussion is required, the *BMJ* ethics committee also needs to develop practical recommendations for the use of case studies where the subject cannot provide full informed consent.

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Competing interests: None declared.

1 Singer PA. Consent to the publication of patient information. *BMJ* 2004;329:566-8. (4 September.)
2 Rogers WA, Draper H. Confidentiality and the ethics of medical ethics. *J Med Ethics* 2003;29:220-4.

More on confidentiality and case material

EDITOR—We welcome the views of the *BMJ* ethics committee.[1] In an article for the *Journal of Medical Ethics* we drew attention to some of the obstacles to gaining consent for publication of case material in ethics.[2] We also reviewed the policy of several general medical and specialist ethics journals and found that many, including the *Journal of Medical Ethics*, gave no instructions on confidentiality.

Given the amount of case material that is used in medical ethics, this is a serious problem that editors may be addressing in any one of several ways: editors recognise the problems highlighted both in our article and in this one and exercise discretion on what to publish; editors do not think that issues of confidentiality are raised when (apparently) anonymised case studies are used; editors have not given sufficient thought to the matter and have no policy; or, editors did not recognise the issue. We were pleased to read that the *BMJ* recognises the problem and the need for editorial discretion in difficult cases.

Two issues are not addressed in the article by Singer.

Firstly, it may not be possible to anonymise a case when the relevant ethical issues tend to make it unique. To cover this possibility, it may be worth revising *BMJ* policy point 3 (ii) to add the public interest in debating important ethical issues to the existing two criteria of clinical lesson or public health.

Secondly, as Newson notes (previous letter),[3] the article makes no reference to the problems of gaining consent for those who are unable to consent for themselves. In our paper, we pointed out that publication is rarely in the patient's own interest (although involving an ethicist in discussions about the patient might be),[2] so that it is difficult to see the grounds on which consent could be given—except perhaps that it is not against the interests of the patient.

Finally, on the question of reporting mistakes, here the issue might not just be one of the patient's consent. What of others involved? What if the mistake was not made by the person hoping to publish the article but by a colleague or associate? In such cases, should the author gain the consent of other relevant parties? If not, why not? And if not, could the principles for not gaining consent be applied to other cases—for example, those where the patient does not wish to give consent?

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Seeking consent is morally essential

EDITOR—Singer writes: "For this reason, you must obtain express consent from patients before publishing personal information about them as individuals in media to which the public has access, for example in journals or text books, whether or not you believe the patient can be identified. Express consent must therefore be sought to the publication of, for example, case-histories about, or photographs of, patients.

"However, the GMC does admit of exceptions in the case of patients who have died."[1]

About three years ago I found that my son's rare heart malformations were written up in a cardiology surgery journal. As I come from a medical family, I had no regrets that it had been done. However, it was immediately identifiable to me because he had an absent right subclavian artery, an interrupted aortic arch, ventricular septal defect, patent ductus arteriosus, atrial septal defect. I knew it was him, but I was not asked for my consent for its release, which I would have readily agreed. It was right that it was written about in the literature because it was rare. It was the lack of consent, however, that bothered me.

I disagree with the exceptions in cases where patients have died. My son has since died from subaortic stenosis, endocarditis, stroke, and congestive heart failure. I would have hoped that the sensitive nature of his case meant that I would be informed of any publication by any of the hospitals involved. Although I would probably have agreed to

publication, I would also have liked to know what was written before suddenly finding it on the internet.

Over the years, I have found many untruths about me in notes and about the condition as a whole. I would like the facts spelt out properly—the word stereotyping comes to mind.

My son and I both have the same rare genetic deletion and syndrome, and it would not surprise me at all if we were "written up" at some stage in the future. Photographs can also cause distress for medical families. We are easily identifiable, but I would like to be asked and I would in turn fully support a doctor who in turn would write "a true and honest report," rather than what he or she seemed to think at the time.

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People with intellectual disabilities

Emotional needs of children with intellectual disabilities are unidentified

EDITOR—Cooper et al discuss the differing needs of people with intellectual disabilities.[1] In recent years health policy documents highlighting the needs of children with intellectual disabilities have been many. Although they recognise the different physical and emotional needs of these children, little is known about this deprived and disadvantaged group.

Intellectual disability has traditionally been an exclusion criterion in research studies. At one time, clinical lore believed that children with intellectual disability did not have behavioural problems and that any inappropriate behaviour displayed was secondary to their mental handicap. This view is not supported by current evidence, recent studies having shown that they are prone to emotional and behavioural problems.[2] These are, however, often underdiagnosed because of issues such as "diagnostic overshadowing," the tendency of clinicians to overlook additional psychiatric diagnosis once intellectual disability has been diagnosed,[3] and "masking," whereby clinical characteristics of emotional and behavioural problems are masked by a cognitive, language, or speech deficit.[4]

Research in children with intellectual disabilities is hindered as most studies do not use standardised diagnostic interviews or criteria, and they are excluded from virtually all treatment studies. This has ethical implications as little is known about diagnosis in and treatment of these children, and they are often undiagnosed and untreated. Further inequalities need to be prevented, and attempts are required to promote high quality research into this disadvantaged group.

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1 Cooper A-A, Melville C, Morrison J. People with intellectual disabilities. *BMJ* 2004;329:414-5. (21 August.)
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People registered disabled with learning difficulties tend to fall through the net

EDITOR—Few of the findings, recommendations, and services being developed for people with learning disabilities, as discussed by Cooper et al,[1] are being applied to people who are registered disabled with learning difficulties. This group seems to fall through the net in today's NHS; there is little to help them, even when progress has been made for intellectually disabled people in general.

Many adults with learning difficulties have common health problems that have not been addressed.[2 3] In many cases neither learning disability services nor mental health services, including the voluntary sector, consider this group of patients to be appropriate for referral, assessment, or treatment. Few agencies deal specifically with learning difficulties. My discussions with adults with learning difficulties indicate that they are at a loss about where to turn for help or advice as any existing support groups are inevitably small, fragmented, and uninfluential in professional circles.

General practitioners also do not know where to refer such patients. The end result is that few treatment options for specialist attention are open to them even when identified medical problems require specialist intervention because of the learning difficulties. This in turn leads to inappropriate referrals and wasted NHS consultation time.

An example is substance misuse and eating disorders (and obesity) among people with attention deficit disorder. Between 25% and 50% of adults with the disorder use alcohol and other drugs, including food, to soothe their symptoms.[4 5] However, adults with untreated symptoms of attention deficit disorder are often assessed by mental health services rather than specialist learning difficulty services in the United Kingdom. Alarmingly, these people commonly have five or more different diagnoses over time, depending on which team is assessing them. This has obvious implications for the consistency of their treatment and the credibility of their diagnoses.

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Feeding tubes in dementia: is there an effective UK strategy?

See also News p 873

EDITOR—In their quality improvement report Monteleoni and Clark showed a reduction in the number of gastrostomy tubes inserted (in patients with dementia) after specific quality interventions had been implemented.[1] We would like to add two points to the debate.

Firstly, how applicable is this observation to the United Kingdom? We have previously reported a high mortality in patients with dementia who have a percutaneous endoscopic gastrostomy (PEG) tube inserted.[2] As a result of this observation we devised a pragmatic strategy to try to improve all aspects of our selection process for insertion of the tube. Our quality interventions are not dissimilar to Monteleoni and Clark but also incorporated a one week, waiting list policy before the tube was inserted (box). We found that this additional quality intervention further improved selection of patients as it provided an opportunity for all those involved in the decision making process to reflect on the implications of PEG tube insertion. The nature and long term implications of a decision to feed mean that carers and relatives have to come to terms with the decision.

In addition, particularly ill patients may succumb during this cooling off period. Like Monteleoni and Clark (but in a UK setting) we were able to show a reduction in the number of PEG tubes inserted in patients with dementia.[3]

The final issue, which is perhaps harder to quantify, is the practice by nursing homes to accept preferentially patients with PEG tubes. This practice is linked to a greater amount of remuneration.[4 5] In addition, the insertion of a PEG tube may potentially reduce the length of stay in hospital and alleviate the pressure on acute medical beds.

Referral strategy for percutaneous endoscopic gastrostomy[3 4]

- Standardise PEG referral form including concomitant disease
- Endoscopy nurse triage and dissemination of published evidence
- Gastroenterological review where necessary
- Holistic and multidisciplinary approach
- Advise against PEG feeding in patients with dementia
- One week waiting list policy

However, these external economic and logistic forces may not be in the patient's best interest.[4 5] In the United Kingdom at least, it is only when this practice is addressed that we will see a global decline in referral for gastrostomy insertion in patients with dementia.

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Liver toxicity and pioglitazone

Data are missing

Editor—The interesting drug point by Farley-Hills et al, on fatal liver failure associated with pioglitazone, is missing data.[1] I hope that it will remind doctors to monitor liver function and not cause a scare similar to that which occurred with troglitazone.[2]

Farley-Hills, for example, did not mention a liver function test before treatment with pioglitazone was started or whether the profile of the liver functions test was monitored after that. The guidance from the National Institute for Clincial Excellence (NICE) and *British National Formulary* both recommended that, as do the manufacturers.[3] No details about glycaemic control were given before blaming the patient's diabetes for his severe liver failure. Was there any reaction to gliclazide before, such as an abnormal liver function test, because gliclazide has been reported before to cause liver derangement?

It seems from the patient's histopathology report that he had chronic liver disease accompanied by fibrosis. Either the clinician failed to follow the guidelines or the screening test for liver function is not robust enough to pick up such disorder and consequently avoid thiazolidinediones.

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Competing interests: PA has given lectures that were sponsored by Takeda to primary care trusts.

1 Farley-Hills E, Sivasankar R, Martin M. Fatal liver failure associated with pioglitazone. *BMJ* 2004;329:429. (21 August.)
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Author's reply

Editor—The liver function tests before starting treatment with pioglitazone gave normal results apart from a bilirubin measurement of 20 and an alanine aminotransferase concentration of 44. His glycated haemoglobin concentration was 8.6, and there was no evidence of a previous reaction to gliclazide.

I agree that monitoring of liver function tests is mandatory but, in this case, liver disease was not found before treatment was started.

As Amin says, given the histopathology report, a more robust test of liver function may have uncovered unsuspected disease. In addition, perhaps the first liver function test check after starting treatment should be sooner than the two months recommended by the National Institute for Clinical Excellence.

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Best estimates of coronary risk of passive smoking are needed

Editor—Whincup et al show passive inhalation of environmental tobacco smoke to be an unexpectedly strong risk factor for coronary heart disease, when assessed using serum cotinine concentrations, in contrast to Enstrom and Kabat, who did not.[1 2] They emphasise the need for further prospective studies using biomarkers.

We measured serum cotinine concentration and other biomarkers of smoking at baseline in our Scottish heart health study and Scottish MONICA surveys and recently reported cardiovascular mortality in never smokers, finding excess risk with passive smoking[3 4]; preliminary work has now been extended to include morbidity and mortality at 16 years.

Using biomarkers and questionnaire results we found discrepancies between self-reported exposure and serum cotinine concentration in passive smoking.[3] Cotinine results are affected by individual differences in nicotine metabolism and by time delays from exposure. Because of this we have found a combination score of grades of self-reported exposure and of cotinine valuable.[4 5]

Campaigners against tobacco tend to talk-up positive results on passive smoking and to discount weak or negative ones as "flawed" for non-scientific reasons. To obtain the best overall estimates of risks of exposure to smoke without bias is important. Nicotine itself is unlikely to be responsible for the risk of passive smoking, but cotinine is a useful biomarker of a recently common, now disappearing, form of smoke exposure. Banishing the traditional clouds of tobacco smoke forever may be dear to the hearts of many of us for social as well as medical reasons, but were any exposure to smoke from combustion of vegetable matter, however caused, to be labelled dangerous this might have severe long term occupational and economic consequences. It is important for that reason to get the best estimates of risk that we can.

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Salt tax could reduce population's salt intake

Editor—Eaton's news item on the campaign to reduce salt intake by the UK's food safety watchdog describes processed foods as a key factor in high population salt intakes.[1] A comparatively simple way to reduce the use of salt by manufacturers of processed food would be to introduce a salt tax.

The potential public health and economic benefits of a salt tax as part of a range of interventions reducing salt has been identified in modelling work.[2] Good evidence exists around the impact of existing excise taxes on protecting public health from tobacco related harm and alcohol misuse.[3 4]

Furthermore, the revenue from a salt tax could be used to fund information initiatives on nutrition or to subsidise an expansion of programmes that provide nutritious foods (such as fresh fruit) to schoolchildren. Such uses of the tax revenue would also be important to ensure public acceptability of a salt tax.

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The three paradoxes of private medicine

Hypocrisy, shock, and embarrassment were trivialised

Editor—I read the personal view column always with interest, mostly with pleasure, sometimes with sadness, but rarely with the mixture of disbelief and anger I experienced about "The three paradoxes of private medicine."[1]

Firstly, the opening paragraphs reveal hypocrisy usually heard from Labour politicians who defend sending their children to private schools. So private medicine stinks, but, when it suits my family I am going to make use of it.

Secondly, it was hard to believe how shocked Longley was to be faced with courtesy and politeness by the staff he encountered. What does this say about the NHS? In my general practice we employ 34 staff and spend time training them to deal with the general public in a polite and sensitive way—not always an easy task—and I hope not with the same contempt Longley aims at the private sector.

Finally, he faced the embarrassment of being asked to pay for private treatment. What did he expect to happen, and how did he expect it to take place? Would he have preferred to pass cash across the desk to his consultant, or maybe, as a fellow doctor, was he hoping to be let off?

In the same issue there was a deeply moving and thoughtful account of the hardships faced by patients in the south Caucasus.[2] Alongside this the personal view column reeked of smug middle class angst. Please, no more hypocrisy, shock, and embarrassment trivialised in this way.

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1 Longley MJ. The three paradoxes of private medicine. *BMJ* 2004;329:579. (4 September.)
2 von Schoen-Angerer. Understanding health care in the south Caucasus: examples from Armenia. *BMJ* 2004;329:562-5. (4 September.)

Private medicine stinks

Editor—Longley is a man after my own heart. His personal view on private medicine is gloriously disputatious, and he has it bang to rights.[1] I received an unctuous letter on embossed paper recently that declared "What a pleasure it was to meet your charming patient Mrs X . . . I think she has Y, but for the sake of completeness, I have ordered a number of (expensive) tests and will see her shortly with the results. In the meantime I suggest she takes Zamzam XL and Zipzip MR."

I see Mrs X a couple of days later as an emergency because Zamzam and Zipzip are too expensive for her to buy privately and would I please prescribe same instead (non-generically of course)? I feel angry and manipulated.

Two weeks later the second letter arrived. It's been a triumph for Zamzam, and the impoverished Mrs X is now to be slotted nicely back into the NHS.

It happened again yesterday.

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1 Longley MJ. The three paradoxes of private medicine. *BMJ* 2004;329:579. (4 September.)

The golden dustman cometh

Editor—When I was a lad, a visit to the general practitioner cost a guinea (Australian), the radio plays came from the BBC (using Australian actors assuming British accents), England was still Home, at least to the older generation, and my reading was all W E Johns and Frank Richards. During my studies, Davidson, Hutchinson, and Hamilton Bailey painted a world view of medicine (admittedly somewhat Dickensian), which I absorbed and which left me feeling that, somehow, I understood the British way.

I thought I knew a bit about the NHS too, but when I read Longley's lament over receiving some politeness and prompt treatment, I realised that I knew nothing.[1] I was looking into the Heart of Whatness. This is the great British inscrutability. They are Frenchmen with whom we just happen to share a common language.

How, I wondered, can one put into words what the NHS means to Longley and these foreigners? And then I remembered that Dickens had done just that in *Our Mutual Friend*.[2] Here, Mr Nicodemus Boffin, a praeternaturally wise and generous working man, has inherited a vast fortune derived from recycling household waste and uses this wealth to do good works. In Boffin's dust mounds great masses of waste and decay are miraculously transformed into gold. I felt much better for having this insight, but I remembered also that ultimately the carts arrived and toiled night and day, until the mounds were all gone.

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1 Longley MJ. The three paradoxes of private medicine. *BMJ* 2004;329:579. (4 September.)
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Summary of responses

Editor—The online debate of Longley's personal view starts with criticism of the author, followed by attempts to understand his rationale and psychology and a general discussion of public and private healthcare systems and their political implications, ending with examples—positive and negative—of the results of their coexistence.[1]

Most correspondents take issue with Longley's three paradoxes: paying for health care can be disempowering, private medicine does not seem to cost anything, and the joy of clinical resolution is tainted by shameful feeling of compromise and guilt. Many find nothing wrong with paying for private medicine, but if someone doesn't like it, he or she doesn't have to do it, as "not everyone is cut out to travel." Payment for service is not a reason to suspect ulterior motives in staff—after all, even staff in the public sector are motivated by money, in the shape of a salary.

Several correspondents try to analyse where Longley's feelings of guilt might originate. The fact that the UK population has become used to poor service since the second world war—and that this attitude is endemic—is one candidate. On the whole, correspondents agree that hypocrisy is worse than shame or guilt, and some point their fingers at the author for this.

One correspondent illustrates with her own experience that the NHS is not worse than private care; another reminds us that Longley would have reached the reverse conclusion—private care is no better than the NHS—if his expensive private consultation had resulted in a year long wait till the next appointment. And a third rightly points out that it's not NHS care that is poor but access to it.

A US practitioner asks why it is acceptable to be taxed for care and have to pay again to get decent customer service and, further, why every patient should not have the choice that paying with real money brings. A general practitioner from Southampton reminds us that certain essentials in life—housing, food, water, clothing—are not free either, so why expect something less essential to be?

Two correspondents illustrate with examples what is intrinsically wrong with private medicine in the United Kingdom: it enables people with money to jump the queue before being put back into the public system. This may be a serious drain on resources, but it also begs the question whether anyone with money or initiative, or both, should have that advantage.

In contrast, Switzerland and France are cited as examples of countries where a combination of private and public systems works well, and a London based fertility specialist explains how private and public medicine together have advanced medical research in the United Kingdom. Maybe another US doctor has a point when he says that Longley should celebrate the strengths of both systems instead of shedding crocodile tears?

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Competing interests: None declared.

1 Electronic responses. The three paradoxes of private medicine. bmj.com 2004. http://bmj.bmjjournals.com/cgi/eletters/329/7465/579 (accessed 6 Oct 2004).