The ethics of confidentiality in teaching and research†

INVITED COMMENTARY ON... RE-EVALUATING CONFIDENTIALITY

Peter Tyrer

Draper & Rogers (2005, this issue) have put an important subject under the ethical microscope. They have demonstrated that the current, fairly simple, rules applying to the publication of case studies and dissemination of patient information in teaching are inadequate and need revision. This is particularly important because such forms of communication are likely to increase in the future. Many journals, including the *British Journal of Psychiatry*, generally frown upon case studies as representing little value to science: case studies unnecessarily focus on the particular; their message is only valuable when it is general. However, they aren't going to go away because their educational value is obvious, as anyone who looks at the handling of almost any scientific subject in the mass media will testify. Experts can pontificate on hypotheses, proportions, means and significance to little effect and the real message comes home from a sufferer or successfully treated patient who adds human flesh to a dry factual skeleton. This need to particularise is necessary in all parts of teaching.

Violation, indiscretion and secretiveness

We live in a curious society in which we are becoming ever more open with regard to freedom of information but ever more protective towards the disclosure of personal information. Thus, the public's right to know and the Data Protection Act often seem to be on a collision course, as recent controversy over the Ian Huntley case and the Soham child murders illustrates. We cannot afford to be secretive and yet if this provokes feelings of violation we have to be.

The goal posts have shifted in the past 20 years and the old utilitarian hypothesis that we should do the greatest good for the greatest number, a common justification for participating in research which has no direct benefit to the individuals taking part at the time, has been replaced by the even older *primum non nocere*, above all do no harm.

Anonymisation and equity

Draper & Rogers make a strong case for better use of anonymisation in teaching and publication. This is certainly a way forward and definitely justified, as so much of the personal information given in case reports for teaching purposes is redundant to the main message. Unless we can tackle the problems of disclosure and potential violation we are in danger of retreating to a defensive position whereby we publish and teach using only an extreme minority of patients who are narcissistically keen for their special problems to be exposed to the world. I have great sympathy with Draper & Rogers' suggestion that

> 'unless incompetent patients participate in research, as a group either they will not benefit from it or benefit will be retarded as advances resulting from trials on competent patients will be applied on an individual and ad hoc basis'.

This problem is prominent in conditions such as learning disability, in which enlightened views of care have not been accompanied by similar enlightenment in research (Fraser, 2000; Oliver *et al*, 2002). Similarly, if patients who feel potentially violated or discriminated against for other reasons do not take part in teaching and research, as a group they are likely to suffer because their special need will not be taken into account by those who are involved in developing guidelines and treatments for these individuals. We have to re-establish the message that good teaching and good research benefit everybody and the difficulties in achieving them should never become personal obstacles.

†This is the first of two invited commentaries on this article. For the second see pp. 123–124, this issue.

References

Draper, H. & Rogers, W. (2005) Re-evaluating confidentiality: using patient information in teaching and publications. *Advances in Psychiatric Treatment*, **11**, 115–121.

https://doi.org/10.1192/apt.11.2.122 Published online by Cambridge University Press

Fraser, W. I. (2000) Three decades after Penrose. *British Journal of Psychiatry*, **176**, 10-11.
Oliver, P. C., Piachaud, J., Done, J., *et al* (2002) Difficulties in conducting a randomised controlled trial of health service interventions in intellectual disability: implications for evidence-based practice. *Journal of Intellectual Disability Research*, **46**, 340-345.

Peter Tyrer is Professor of Community Psychiatry and Head of the Department of Psychological Medicine at Imperial College (Charing Cross Campus, St Dunstan's Road, London W6 8RP, UK. E-mail: p.tyrer@imperial.ac.uk), and an honorary consultant in rehabilitation psychiatry with Central North West London and West London Mental Health NHS Trusts. He is the current Editor of the *British Journal of Psychiatry*.

History is bunk†

Invited commentary on... Re-evaluating confidentiality

Gwen Adshead

Draper & Rogers (2005, this issue) discuss the publication of case studies in psychiatry. They raise an issue in relation to consent that I would like to pursue in more detail: namely, what is it that we are asking patients to consent to when we ask them to participate in research?

Draper & Rogers suggest that minors and incompetent psychiatric patients pose similar problems for consent, not least because the publication of their histories is not in their individual interest. Although there are similarities with legal minors, I think that psychiatric patients differ from children in significant respects. Eliding the two groups is not helpful, because adults with psychiatric problems are not children, and there is a real danger that patients will feel patronised and controlled in demeaning ways.

But a more crucial issue is actually whether it is true that psychiatric patients (and, indeed, children) are *not* competent to consent to publication of data about them. This depends on what it is that we are asking them to do. I suggest that we are asking them (a) to take a small risk that their privacy will be invaded and (b) to do this for an altruistic purpose for the benefit of others.

Both of these decisions are more complex than most ordinary treatment decisions. Do they need a higher demonstrated level of competence? It is possible to argue that taking a risk to benefit others, without any possible benefit to the self, is a more demanding choice to make, in terms of duties, consequences, virtues and so on. *Prima facie*, it might seem that psychiatric patients and minors will not be able to do this. But the research does not bear this out. Priscilla Alderson's research shows that children as young as 10 can make complex treatment decisions, involving life and death (Alderson, 1992). Appelbaum (2004) cites evidence that patients with serious mental illness are still able to consent to research participation. It is a mistake to assume that psychiatric patients and children lack competence to make complex decisions; each person's competence will need to be assessed.

†This is the second of two invited commentaries on this article. For the first see pp. 122–123, this issue.

Consent

I have argued elsewhere (Adshead, 1997, 2003) that the choice to participate in research is fundamentally different from making treatment decisions, because it involves the decision to be altruistic. I have also argued that because of this difference, it is crucial to retain the distinction between therapeutic and non-therapeutic research. Draper & Rogers hint at this in their article, and I emphasise it because it has been suggested by our own College that this distinction should be dropped (Royal College of Psychiatrists, 2000). Quite apart from the fact that it is not possible to abandon conceptual distinctions just like that, the key issue here is about what it is that research participants are being asked to do, whether it is in terms of consent to disclosure for research, or consent to participate in a trial. For therapeutic research, the participant is being asked to help others, while taking a chance that they might benefit. For non-therapeutic research, participants are asked to help others, and take a chance that they may be harmed.

Clearly, researchers (including those who seek to present case histories) are under a duty to protect research participants as much as possible, and not

https://doi.org/10.1192/apt.11.2.122 Published online by Cambridge University Press