Recording health care and sharing the information – more bureaucracy or a welcome challenge to prevailing practice?

The NHS Plan (2000) outlines a number of strategies that respond to the consumer agenda and enhance the notion of patient and public involvement in all aspects of healthcare. While there are considerable changes ahead in the ‘macro’ whole service-related involvement of patients and public (patient/public involvement strategies, health service scrutiny by local authorities and the development of foundation ‘hospitals’), there has been a revolution in the expectations of the patient and their carers regarding choice, access to information about treatments and diagnosis, and rights of access to all clinical information.

The NHS Plan (2000) outlines the intention for patients to receive copies of all clinician-clinician correspondence by right if they so wish by April 2004. It is not often that a relatively quiet policy initiative brings in its wake a major change in practice for most clinicians. The last time this happened in mental health care was the introduction of the care programme approach in 1990. It is likely that copying letters to patients will rapidly be followed by a number of related policies, responding to consumer rights and expectations. One possible explanation for this is that in this area, clinical practice has lagged well behind the public will. Clinicians are increasingly facing up to the challenge that everything they record on any aspect of patient care is open to external scrutiny at any time. If it is not by the patient or carer, then it is by others, including Mental Health Act Tribunals, solicitors, the Data Protection Commissioner, the Health Service Ombudsman, health service managers and, alas, the coroner.

A case is often made that mental health services are special, and that the consumer agenda is driven by other health services. In certain cases this may be so, but there is little comfort for psychiatrists in following this route and every indication that (except in a few exceptional cases) the rights of access, the involvement of patient and public and the notion of full patient choice is a policy expectation in mental health, as in all other health services. Some mental health practitioners routinely share clinical information with their patients, give good-quality information and have rarely had patients using the formal ‘access to healthcare records’ route. They may be somewhat puzzled by enshrining what is good, sensible and flexible practice into a bureaucratic programme with targets and monitoring. In this edition of the Bulletin, a number of papers address aspects of sharing of information with patients and with others.

Currently, the health record is mostly a paper-based repository (the clinical casenote) for all written communications relating to an individual patient. Health care records should provide a sequential and confidential record of the documentary evidence of the management of care. These health records are regularly being scrutinised by the patient and/or carers, and increasing care needs to be taken in what we write, and how we record both direct and third party information. Patients are gaining access to the notes through ‘access to healthcare records’ as of right, and it is worth noting that a clinically-led refusal to divulge all or part of the healthcare record is based solely on the notion of ‘significant’ harm to self or others. It is important that clinicians are able to justify a decision to refuse access, up to and including a full explanation to the Data Protection Commissioner. Clinical supervision of doctors and other staff provides a vehicle for assisting health care practitioners to develop the skills of record-keeping that stand both the direct scrutiny of the patient and others, and also how to make a series of

Box 1. Doctors taught the art of writing clearer notes – The Times, Monday 9 June 2003.

The leader column expands – ‘A century ago the successful Victorian doctor was said to need four things, A top hat to give him Authority. A paunch to give him Dignity. Piles to give him an Anxious expression. And illegible handwriting to impress his patients with the potency of his Prescriptions, Potions and Pills.’ The leader misses the point somewhat in suggesting that there is no chance of remedial writing classes succeeding, suggesting that the leader writer’s understanding of the challenge to modern doctors lies only in writing legibly. The challenge is increasingly in the clarity, understandability, and thoughtfulness of what is written. And perhaps this is occasionally a somewhat tall order for a busy and often harassed psychiatrist?
clinical entries encapsulating an open clinician–patient relationship that is at once both respectful and therapeutic. Unfortunately, personal embarrassment because of tone and content of what we (or others) have written in the past is not a valid reason for refusing access.

A good set of case notes (or dare one say an electronic health record) should provide easy access to the up-to-date plan of care (including current medication); a full account of the patient’s history, including contacts with health (and where fully integrated, social services) and treatments; any relevant risk information that should influence clinical decision making; contact information for all health and social care professionals; and other key contacts such as housing, schooling, family (nearest relative and next of kin) as a minimum. It should also be constructed and presented in such a way that the patient can relate to the entries, and in many cases benefit therapeutically from the experience of reading (and correcting) them.

Copying letters to patients (including patient held records)

This new NHS-wide initiative poses a significant administrative and practical challenge ahead for the NHS (what’s new?). In addition to the copying of letters, patients have to be asked whether they wish to receive the letters at all, and where they would like the letters to be sent. This provides an added sting to the proposal (asking patients whether they would like to receive the copy of the communication at their very next appointment seems a flexible and less costly response to the challenge?)

Nandhra et al (2004, this issue) instituted the programme of copying letters to 73 out-patients, and received feedback from them. The results are encouraging. Although only 40 of the 73 patients responded, 33 (83%) valued receiving the letters. The authors make some pertinent comments about the guidance that may be useful for mental health services. They suggest that the process of writing to patients was generally well-received by psychiatrists as well, although two psychiatrists in the sample did have particular concerns about the possible distressing impact of the information on their patients. One patient’s letter was sent to the wrong address, and this highlights an area of potential risk for services when the practice is introduced widely this year.

Lloyd (2004, this issue) reports on a survey of patients attending a liaison psychiatry clinic after copying the correspondence to the referring specialist and general practitioner. A relatively large number responded to the postal survey (52%) and those who responded were overwhelmingly in favour of receiving these letters. He goes on to point out that the copying of letters is in keeping with the greater openness that is being adopted in modern clinical practice. He outlines the need for letters to be written in a particularly clear, jargon-free style, and also the challenge of respecting the patient’s wishes in what information is included or not. He suggests that most doctors would support the copying of letters to patients, but that more evaluation is required, adding that perhaps particular problems may be experienced where patients do not share the professionals’ views of their problems (community psychiatry, forensic psychiatry) and for older adults services. A number of reports from the pilot sites are now on the Department of Health website (www.doh.gov.uk/patientletters), but there is nothing to suggest that particular services will be exempt. Perhaps Dr Lloyd is being too cautious on behalf of community, forensic and old age psychiatry, and that copying letters to patients even in the most challenging of situations could actually enhance the therapeutic relationship where it has been quite tricky. Child and adolescent mental health services pose a challenge, but probably not an insurmountable one.

Even more challenging, more engaging, and providing a solution to notes being lost, is developing patient held records in mental health. Laugharne & Henderson (2004, this issue) provide an overview following a systematic literature search. They describe a number of interesting studies, particularly in community mental health, with patients suffering from psychotic illnesses. The number of patients with psychotic illness using the patient-held record was surprisingly high. However, they do comment that anecdotally the patients who chose to hold their own records were generally easier to engage and collaborated with services. The paper concludes that as yet, there is no research evidence that would support widespread use of patient-held records. However, they make the point that there is more work to be done in understanding why some patients offered them choose not to use them, and looking perhaps more radically at the patient group who do choose them, specifically measuring patient empowerment and patient–professional communication using a more appropriate methodology. As we get closer to the development of the electronic record, it is quite likely that technological advances will have delivered a more effective patient held ‘smart card’ as an adjunct to the record. The ultimate patient-held record?

Confidentiality and sharing of information

The expectations of doctors are clearly laid out by the General Medical Council in Confidentiality: Protecting and Providing Information (General Medical Council, 2000). There is a clear and well-established standard that patients will be consulted on the extent to which confidential information will be shared by other health care professionals. In mental health, and any other service where care is delivered extensively via multi-professional clinical teams, it is possible still rather unusual for patients to be given explicit written information (and choice) that they actually sign up to as to how their personal information is to be used, and the extent of the team-based discussion of their problems. Normally, the issues of confidentiality and disclosure of information fall to the consultant within a clinical team, although obvious exceptions to this rule include psychological therapies and psychotherapies where the clinical psychologist or
therapist is being asked to disclose information. In those cases, the Caldicott Guardian would advise.

Care clearly needs to be taken when disclosure of information is considered (and without patient consent it is useful to assume that all patient-related information is confidential. The statutory requirements for disclosure are helpfully laid out in Royal College of psychiatrists, 2000) and Dr Dolan, in her overview on disclosure (Dolan, 2003) outlines the responsibilities and limitations (and liabilities) in arriving at such decisions. Whatever decision is taken, and whatever disclosure is decided upon, it goes without saying that clear and accurate records of these decisions should be made, and are best done within the patient health record.

Clinicians are perhaps lagging behind public expectation and legal scrutiny in the rigour we apply to record-keeping. We occasionally scapegoat ‘the clinical records staff’ and ‘the notes’, rather than working to improve the quality of data entry and communication. In addition, we need to ensure that we are training clinicians, and in particular young psychiatrists, to avoid the jargon-ridden and often obtuse prose we have often resorted to, both in written and verbal communication with our patients and professional colleagues. Access to records, greater openness and the requirement to copy all correspondence to patients will pose a welcome challenge. Yes, mental health is somewhat different. However, by establishing that mental health patients have the same rights of scrutiny, choice, access, and of course assurance of confidentiality, despite the exceptional difficulties particular to mental health services, it is possible that these new developments could make a significant contribution to reducing stigma and alienation. The traditional options for clinician refusal to divulge information to the patient and/or carer, and to account for clinical decision-making, is rapidly diminishing. This should not be confused with the core role of the psychiatrist in maintaining the confidentiality of patient information on behalf of the patient while society and healthcare delivery is pushing at the information boundary.

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David Roy  Medical Director, South London and Maudsley NHS Trust, 9th Floor, The Tower Building, 11 York Road, London SE1 7NN.