AIMS For a better birth...

Instant Access

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Jean Robinson suggests that information sharing should extended to patients

I have been wondering for a long time why we cannot have instant access to our own health records in the NHS we pay for.

Why do we have to go through the rigmarole of formal application, form filling, and paying a charge of 'up to £50' – which has become the basic fee – for written hospital records? We know from our callers that many people struggle to find such a sum, or simply cannot afford it.
The reason we often suggest to those who contact us that they access ALL their records, is to check for inaccuracies – or in some cases downright lies. In the case of maternity care early access is crucial because if a midwife, doctor or health visitor believes that the embryo, fetus or infant may be at future risk, this may result in a report to social ser vices, and set in train a number of damaging and threatening interventions. We have known a number of cases where such reports have been based on misunderstandings, misinterpretations, or
even downright malice when the woman has made a justified complaint or even has cause to do so.

It is not just maternity and child care, but ordinary patient care too. Being now an elderly great grandma, I have signed powers of attorney for health and social care for my children. If I am unable to take decisions for myself, I trust them to do the best they can for me. And I
would like them to have instant access to my records so that they know what is going on.

Did you know that there is a Maternity and Child Health Database and that your records are on it? You have the right to know what's on it AFTER you have made a formal application. A Children's Database is now being prepared. Parents and older children will have the right to see what's on it – again after they have filled in the appropriate form. Any suspicion of risk or neglect to a child will already have resulted in multi-agency sharing of data – social ser vices, police, schools, nurseries, and possibly any voluntar y agencies involved too. Why are we so worried about multi-agency sharing, which is so common, and has been little questioned? Because we have seen many instances of the problems which arise. These are groups with different professional languages, a different ethos, different purposes, different codes of ethics. And, unlike health care professionals, although they could be sacked, they do not have a code of conduct which could strike them off and prevent them working in that profession again if they breach confidentiality.

Schools, in particular, can leak child protection data like a sieve, and soon all the mothers at the school

gate are likely to know.

The combined story from the agencies ends up as a blend of ‘hard’ data (for example, results of blood tests) and ‘soft data’ (the thoughts of a social worker or health visitor), which can be blended together and give the impression it is all fact.

Social workers are often ignorant about what medical diagnoses can mean, and that they can be wrong. Before the parents can access the original records to challenge them, and produce proof of inaccuracy, the myth has been created and all these agencies have perceptions of them which are very hard to shift.

One of the most horrifying cases I have ever encountered involved two highly respectable parents who had identified a paedophile who was a professional working with children in the NHS. They were puzzled to find that the mother was subsequently viewed as ‘mad’
and was said to have been sectioned for mental illness a number of times. The careers of both were damaged, since the information somehow spread.

It took them years to find out, and prove, that totally false records of her serious ‘mental illness’ had been created in hospitals in different parts of the country in towns she had never visited. I was with them when we obtained the final proof, and I shall never forget it.

AIMS wants everyone who uses the NHS to have the right to see all their records merely by requesting them and producing proof of who they are, and to have instant access to their own data on every Database. A reasonable charge could be made per page for
photocopies. And carers who have powers of attorney should also have that right. If I had not been prevented from seeing my late husband’s records, his care during his final illness would have been so much better.Ihave been wondering for a long time why we cannot
have instant access to our own health records in the NHS we pay for.