

# *Requesting amendments to health and social care records*



*Guidance for patients, service users and professionals*

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The National Information Governance Board for Health and Social Care (NIGB) was set up as part of the Health and Social Care Act 2008 to provide advice and guidance on, and support improvements in, how information is used in health and social care in England.

We heard from patients who were finding it difficult to get changes made to the parts of their healthcare record they disagreed with. We felt these represented a wider issue, so we have produced this guidance which we hope will help you. We have explained what should happen, but how this will happen is down to individuals and organisations.

This guidance has been produced by a group of NIGB members and medical and legal experts. The working group talked to members of the public, GPs, Caldicott Guardians (senior staff in the NHS and social services who protect patients' information) and other staff responsible for health and social care records, all of whom had experience of this issue.

In this document we will discuss:

- the purpose of healthcare and social care records;
- how we believe problems develop in terms of what information records contain; and
- what the law says.

We give guidance about what should happen when people ask to change information in their record. Section 1 is for people asking to change their records and section 2 is for professionals.

The way this guidance will apply to young people will change as they grow up and become more able to make decisions for themselves. Also, as children's records may contain information about their parents, we have used appendix 1 to explain how our guidance will normally apply to children's records.

You can find more information about the NIGB and our work at [www.nigb.nhs.uk](http://www.nigb.nhs.uk).

*Section 1 -  
for patients, service users and the public*



We consider a 'record' to be information about providing health or social care, which identifies the patient or service user, whether they are an adult or a child.

The National Information Governance Board for Health and Social Care (NIGB) strongly believes that health and social care organisations that keep records hold that information for a number of people who have a genuine interest in its accuracy and in using it. As the patient or person using the service - in other words, the 'subject' of the record - you have a personal interest in the record being an accurate reflection of your consultation (including your own views and, in a health record, the process of diagnosis).

If you disagree with what is in your health or social care record, you should do the following:

- 1 Explain your worries to the person who put the information in your record. If that person is no longer available, contact:
  - the clinician (a doctor, nurse, health visitor or other person carrying out a similar role) or social care worker who currently has your record;
  - the chief executive of the hospital which holds your record;
  - the GP practice which holds your record; or
  - the director of adult or children's social services at your local council.

Good communication is very important when dealing with this problem. Everyone involved should try to deal with the problem quickly. For more information, see 'What to do if you disagree with what is in your record'.

- 2 You should always expect that if you disagree with what is in your record, a

note about this will be added. For more information, see 'What to do if you disagree with what is in your record'.

- 3 There may be rare circumstances when it will be agreed that it would be appropriate for an entry in your paper record to be completely removed so there is no trace that it was ever there, but this will not usually be the case (on page 8 we explain in detail why this is). When an entry is removed, there must be a clear reason for this, and information about what has been removed should be put in the record. For more information, see 'About removing information from records'.
- 4 Remember that records contain opinions, and an opinion is not wrong just because you disagree with it. For more information, see 'How problems happen'.
- 5 If you feel that your request is not being dealt with appropriately, you should use the NHS or social care complaints procedures. For more information, see 'If you do not feel that your concerns have been properly dealt with'.
- 6 If your complaint using either the NHS or social care complaints procedure is unsuccessful, you could also complain to the Parliamentary and Health Service Ombudsman (for complaints about health records) or the Local Government Ombudsman (for complaints about social care records). For more information, see 'If you do not feel that your concerns have been properly dealt with'.
- 7 You can also complain to the Information Commissioner. For more information, see 'If you do not feel that your concerns have been properly dealt with'.

# What are records for?

There are many definitions of what a health or social care record is. However, in this document we consider a 'record' to be information about providing health or social care, which identifies the patient or service user personally. Records can be kept in different ways, including on a computer, on paper or a mixture of both. In most cases, records are held by a professional or team providing care or by the organisation they work for. In some cases (for example, maternity and child-immunisation records), the person receiving the care, or their representative, may hold the records.

Originally, individual clinicians and social workers kept records as personal records of what had been discussed with you, what action they had taken and their professional opinions, examination findings, test results and other reports.

Providing health and social care now involves teams of people rather than individuals. So, depending on the services that you have used in the NHS and in social care, you may have several records in several different places, some or all of which may be linked. The teams use these records to co-ordinate your care. The Medical Protection Society says doctors should be able to understand the essential parts of a patient's medical record without having to resort to memory. Medical records should be detailed enough for another doctor (or other health professional) to deal with the patient's case. The same should apply to social care records.

In recent times there has been a change in how health and social care is provided, and people expect to be more involved in decisions about their care. You make informed choices, rather than being directed by a health or social care professional. Records are increasingly becoming information which is shared and that you can look at and be involved in. For

some time, professional guidelines and the law have allowed you to see what is in your records.

The boundaries between health and social care are blurred, so it is not unusual to find some information about health in social care records, and vice versa.

Accurate records are important for making sure you receive continuous care and are safe. They may also be needed for legal purposes (for example, if you wanted to make a claim after a traffic accident). Records are also very important if you make a complaint about the care you have received - not just for you but for the person or service you are complaining about.

In healthcare there are different ways to use records and gain access to them. Some clinicians will tell you what they have added to the record and a small number let you see your electronic record from your home computer. The Data Protection Act 1998 gives you the legal right to see what is in your record, although there are some cases where this is not possible. (For more details on the Data Protection Act, see [www.opsi.gov.uk/acts/acts1998/ukpga\\_19980029\\_en\\_1](http://www.opsi.gov.uk/acts/acts1998/ukpga_19980029_en_1))

In social care, where possible, it is usual for the person putting the information in your record to agree this information with you. If they cannot agree this with you, you can ask to have your comments included in the record. Most local councils are very open about letting you add comments to your record.

There can be several reasons why people disagree over what is in their record.

## **a The information is wrong**

No system is completely free of mistakes, and keeping health and social care records is no exception. Occasionally, mistakes will be made - the records of people with the same name and similar dates of birth could be mixed up without it being noticed, test results could get put in the wrong record, or a professional could add the wrong information.

## **b The facts are correct but you want certain parts of your record removed**

People naturally worry about other people sharing or seeing very sensitive information without their full permission. You may want to avoid this by having parts of your healthcare or social care history permanently deleted and, sometimes, to have no sign in your record of them having been deleted.

## **c The difference between 'fact' and 'opinion'**

Health and social care records contain facts, but also opinions, judgements and decisions made based on the information the care professional knows at the time.

In healthcare, making a diagnosis often happens in steps rather than a single event, and health professionals need to be able to record their thoughts at a particular time, even if the 'facts' are not totally clear. It can be easy for opinions and facts to be confused. Professionals should make it clear in the record which information is there not as confirmed facts, but to help the diagnosis and treatment. This is especially important if you disagree with anything in your record and you want to have your own views put in the record.

## **d Information given by, or about, another person**

Records may include information reported by or about another person which the clinician or social care professional thinks is important enough to be included. (Professionals often call this 'third party' information.) Details of the health and social care professionals involved in your care is not third party information.

If there is information about someone else or supplied by someone else in a record, it should be clearly marked. Clinicians and social care staff should take reasonable steps to make sure information is accurate before they record it, and, if appropriate, try to find out from you whether the information is correct. If professionals find that information is not accurate or that it has been reported maliciously (that is, with the intention to cause harm), they should say this in the record. They may also feel it is appropriate to remove the information from the record if it has not already been used to make a decision.

Under the Data Protection Act 1998, when you ask to see what is in your record you should be able to see as much information as possible. However, in some circumstances, you may not be able to see any information which could identify another person, unless that person agrees that you can see it or the person who holds the record feels that, given all the circumstances, it is reasonable to give the information to you without the other person's permission.

## About removing information from records

Some people think that mistakes in records should be completely removed so that no-one can tell that they were ever there. With health and social care records, this is not the case, and it is not safe, for you or the professionals providing your care, for information to be completely removed.

The organisations which advise, support and give guidance to doctors nationally, the Information Commissioner's Office and the National Information Governance Board for Health and Social Care all agree that the information in health and social care records should never be changed or removed without an explanation being recorded.

Records are a history of the care or treatment you have had. They often contain large amounts of information, including your opinions, details of the treatment and care you have received, test results and the opinions, judgement and advice used by health or social care professionals to make decisions about your care. The main reason for keeping a record is to support you.

Providing care and treatment is often complicated and based on trust between you and the professionals providing it. Professionals will usually make decisions about care or treatment based on what happened or what was done previously. For this reason, it is important to you and the professionals that the whole record (including any amendments, who made them, and why) is available.

Completely removing one or more pieces of information from a record so that no one knows it was ever there can be like taking a chapter out of a book - the following chapters often do not make sense.

If information is removed and there is no trace that this has happened, it can make it difficult for professionals to understand the record, and it may not be reliable. This can create two problems.

The first is that not having the relevant facts available about your care or treatment may, in some circumstances (such as in an emergency), put you at risk. The second is that if something goes wrong, you might not be able to show that you were given poor advice, care or treatment. Also, the professional might not be able to show that they provided good advice (for example, on the side effects of drugs).

If you ask to have information removed from your record, the professional will have to take account of the importance of having a complete record.

Information is normally removed from a paper record by drawing a line through it and adding a comment to say why it is being removed. This shows that the information should be ignored, and explains why, but means the record is still complete.

We accept that there may be rare circumstances when, after a full risk assessment, which involves the person the record is about, it will be agreed that information will be completely removed from a paper record leaving no trace that it was ever there. We cannot say when and why this might happen as it will depend on the risks and benefits in individual cases.

An advantage of new modern electronic records systems is that they automatically keep information about what has been changed in a record, when it was changed and who has changed it. This information is called an 'audit trail'. People who need to see your record for care purposes will not be able to gain access to the audit trail. This means that information can be removed from your record, but the audit trail will always keep the record complete. Information in the audit trail must stay complete.

When someone asks for information to be removed from their record (whether



electronic or paper), they must be made aware of any potential consequences for their future care. There must also be a clear explanation of the reasons for removing the information and we would expect the following to be recorded:

- The fact that information has been removed;
- The justification for removing it;
- The date the information was removed; and
- The person who removed the information or authorised this to happen.

This would allow the patient to be asked about why the information was removed, if necessary.

When the professional holding your record feels that information should be removed from it, they should tell you, ask for your permission and record this. They do not need to do this if they are removing something which is not relevant to your care or medical treatment.

In June 2009, the Information Commissioner agreed that if a patient asks for all of their summary care record (summary care records are part of the NHS Care Records Service) to be removed, and the record has not been used for clinical care, the record should be completely deleted, without keeping an audit trail of its contents. This fits with our guidance, as information is not entered directly into the summary care record - it comes from other electronic record systems (for example, GPs' systems). The Information Commissioner is not suggesting that the information in those other electronic records systems should be deleted, and so the original records and audit trails remain complete.

# Using information from records for purposes other than for providing care and treatment

In 2007 the Care Record Development Board published a report on what are called the 'secondary uses' of patient information (see note 1 below). 'Secondary use' means using your information for purposes other than providing care and treatment. This could include, for example, managing the NHS or carrying out research.

We have considered what should be done if information which is sent to a national electronic system for secondary uses is later found to be incorrect and is corrected in the system used for directly providing care.

If it is possible to identify you from your information, we believe there should be a process in place to correct this. If that is not possible, the parts of the information which identify you should be removed, or the record should be deleted in the secondary uses system. In other words, we accept that

there may be a need to delete entries from electronic systems which are used just for secondary purposes. As mentioned earlier, we believe that information can, and should, never be completely removed from both an electronic record and the associated audit trail of electronic systems which are used to provide care and treatment.

If it is not possible to identify you from your information, we believe that the organisation holding the information should decide whether it would be practical to change it.

We recognise that this is complicated and feel that the NHS Information Centre for Health and Social Care should consider this problem and produce guidance.

## Note

- 1 The Care Record Development Board Working Group's report on the 'Secondary Uses of Patient Information', August 2007. Available at [www.connectingforhealth.nhs.uk/crdb/workstreams](http://www.connectingforhealth.nhs.uk/crdb/workstreams)

# What to do if you disagree with what is in your record

Health and social care organisations that keep records hold that information for a number of people who have a genuine interest in its accuracy and in using it appropriately. As the patient or person using the service - in other words, the 'subject' of your record - you have a personal interest in it being an accurate reflection of your consultations (including your own views and, in a health record, the process of diagnosis).

## *Our guidance on disputes over the content of records*

- If you disagree with something in your record, the first thing you should do is to raise your concerns with the person who added that information. If that person is no longer available, contact:
  - o the clinician or social care worker who currently has your record;
  - o the chief executive of the hospital which holds your record;
  - o the GP practice which holds your record; or
  - o the director of adult or children's social services at your local council.

Good communication is very important when dealing with this problem. Be clear about what your concerns are and how you want them to be put right. All the people involved should try to settle the matter quickly.

- If you are worried about raising the matter yourself and you are concerned about a health record, you should ask your local Patient Advice and Liaison Service (PALS) for help (see [www.pals.nhs.uk](http://www.pals.nhs.uk)). Every NHS trust has a PALS to provide confidential advice and support to patients, families and their carers. As one of their roles is to provide confidential help in dealing with

problems and concerns quickly, you may find that they can help you to find a satisfactory solution. You can use NHS Direct (call 0845 4647 or go online to [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)) to find the contact details of your nearest PALS.

- NHS Direct, your local Citizens Advice Bureau (or Age Concern, if appropriate) can provide advice on complaints about the NHS or social care.

## *What you should expect to happen*

- In all situations where you disagree with your record's contents, a note about this will be added to the record.
- If information about you is incorrect, this will be corrected and a note added explaining what was corrected, why, by whom and when. 'Corrected' does not necessarily mean deleted without trace. The Data Protection Act 1998 gives you a right to expect that any record about you will be accurate.
- If you are disputing an **opinion** in your record, you must remember that an opinion is not incorrect just because you, or another professional you ask, disagree with it. You should also note that opinions can change or vary and that keeping previous opinions (even if they are eventually shown to be wrong) can be important in understanding the care process. In all situations, a note of your concerns will be added as explained above.

We looked at the web pages of several social services departments and they all made it clear they would do this. In healthcare, both the Medical Defence Union and the Medical Protection Society have agreed that this is an appropriate way of dealing with such a problem, and we believe this model reflects best practice.

# What to do if you disagree with what is in your record

At the time we produced this document (May 2009), the Department of Health guidance (see note 2 below) advises clinicians to agree to add a comment to a record if the patient:

- asks for this; **and**
- has used the NHS complaints procedure (see note 3 below); **and**
- has complained to the Information Commissioner.

We disagreed with this approach. We believe that patients should not have to make a formal complaint to get a comment added to their record. We have advised the Department of Health that it would be appropriate to revise its guidance on this and it has agreed to do this.

## *If you do not feel that your concerns have been properly dealt with*

- You should use the formal complaints process of the organisation you have been dealing with.
- You can find information about making a complaint about an NHS or a social care organisation by calling NHS Direct on 0845 4647 or going to their website at [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk). Local NHS organisations will give you information about their complaints procedure. Your local council's social services department can give you information about their complaints procedure, or you could visit

[www.direct.gov.uk](http://www.direct.gov.uk). Your local Citizens Advice Bureau (or Age Concern, if appropriate) may also be able to provide advice on complaints about the NHS and social care.

- If your complaint is about an NHS organisation, your local Patient Advice and Liaison Service (PALS) can tell you how to make a complaint to the NHS organisation which holds your record. The PALS can refer you to the Independent Complaints Advocacy Service (ICAS) if you need help with making a complaint. Again, NHS Direct can give you the contact details of your local PALS.
- If you are not happy with the result of your complaint, you can refer the matter to the Parliamentary and Health Service Ombudsman (health) or the Local Government Ombudsman (social care). You can also complain to the Information Commissioner, but they will only get involved after you have contacted the organisation concerned and given it an opportunity to put things right (see note 4 below). The Information Commissioner can assess whether your information has been used in an appropriate way under the Data Protection Act 1998. Although the Information Commissioner can issue an enforcement notice to make the organisation keep to the Data Protection Act, they usually only do this in cases where the organisation has broken the conditions of the Data Protection Act in a serious way, or repeatedly.

## Notes

- 2 Department of Health guidance on access to health records - [www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Patientconfidentialityandcaldicottguardians/DH\\_4084411](http://www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Patientconfidentialityandcaldicottguardians/DH_4084411)
- 3 NHS complaints procedure - [www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx](http://www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx)
- 4 Information Commissioner's Office, 'Data Protection Act 1998 - When and How to Complain', page 4. See [www.ico.gov.uk/upload/documents/library/data\\_protection/practical\\_application/dp\\_how\\_to\\_complain\\_final.pdf](http://www.ico.gov.uk/upload/documents/library/data_protection/practical_application/dp_how_to_complain_final.pdf)

## ***'Significant damage or distress' - section 10 of the Data Protection Act 1998***

The Data Protection Act deals with 'processing information' and this includes keeping and using information. If you feel, and can show, that keeping some information about you in your record is causing you a significant amount of unnecessary damage or distress (the Act calls it 'substantial and unwarranted'), section 10 of the Act (see note 5 below) allows you to write to the organisation concerned asking that they stop keeping or using the information. You will need to quote section 10 and give the specific reasons for why keeping or using the information is causing, or is likely to cause, you significant, unnecessary damage or distress. If they refuse and you do not accept their reasons, you can take the matter to court to stop the organisation from keeping or using your information. However, you do need to be aware that section 10 is a complicated part of the Data

Protection Act and that there are several exceptions under which it does not have to be enforced. For example, it does not apply to a record which has to be kept by law.

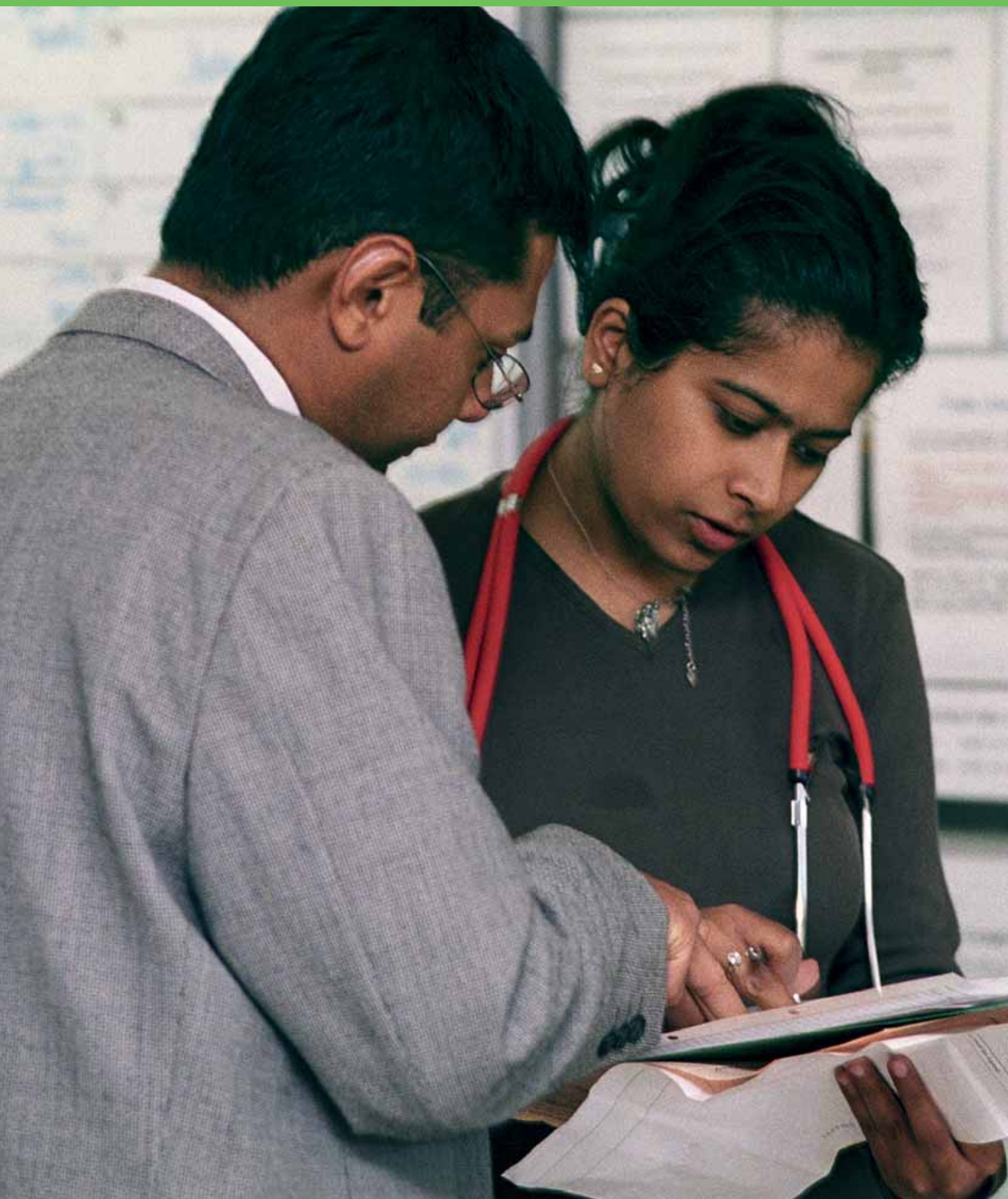
Some people may want to use section 10 to have removed from their record factually correct information which they do not want anyone to see. If you want to take this step, you should have tried all other ways of getting your record amended and also have considered what effect removing the information could have on your care and treatment, including on decisions that might need to be made in the future. Ideally, you should have discussed this with a professional who understands the content of your record.

Every NHS and social care organisation will have one or more people responsible for overseeing how the information they hold is handled. This person (or people) may be called the Caldicott Guardian, the Information Governance Manager or the Data Controller. They may be able to help and give you more advice.

### **Note**

5 Data Protection Act 1998, section 10 - [www.opsi.gov.uk/acts/acts1998/ukpga\\_19980029\\_en\\_3#pt2-l1g10](http://www.opsi.gov.uk/acts/acts1998/ukpga_19980029_en_3#pt2-l1g10)

*Section 2 -  
for professionals*



In all situations where a person disagrees with the content of their record, you should add a note of this to the record.

Most examples of disagreements over a record's contents seem to be caused by opinions in the record. When we were preparing to produce this guidance, we were made very aware of the stigmas people suffer when inappropriate or provocative comments or opinions are added to their record. We take this very seriously, and we expect that all health and social care professionals will share our concerns and always act appropriately.

You should always remember that patients have a legal right to see their record. You should make sure that you fully consider the opinions you plan to include in a record, and that you can justify them as being a necessary part of the patient's care.

Patients, service users and other professionals can be given access to health and social care records in circumstances other than when treatment or care is being provided. As a result, when you add your comments or opinions to a record, you should consider how these might be viewed by the patient, service user or another professional and also how they might reflect on you in the future.

We recognise the challenges of providing treatment and that the steps in a different diagnosis can often blur into opinion. For this reason, when you are recording an opinion you should make it clear that it is opinion and, if the opinion came from someone else, include who gave it and when. If possible, you should also include the contact details of the person who provided the information.

We believe that you should, wherever possible, discuss with the patient what you are going to put in their record, as this will

make it less likely that disputes will arise in the future.

Occasionally, you will need to include information in the record which third parties have reported to you in confidence. If this is the case, you should only include this information if you believe it is serious enough and important for the person's care to justify including it in the record. Information from third parties should be clearly labelled. Under the Data Protection Act, you must take reasonable steps to make sure the information is accurate before you add it to the record, and, if appropriate, when you next have contact with the patient.

You should make sure that paper records are appropriately structured so that, if someone disputes the accuracy of the information, you can include that person's view in such a way that their concerns are clear.

In our advice to service users and patients we have been very clear that the first thing that they should do if they are concerned about the content of their record is to talk to the person who created the entry or the person who now holds the record. It is clear that good communication with people on what the information means, its context, why it has been recorded and how 'fact' may be different from 'opinion' are vital in settling most concerns. It is important that you give enough weight to the patient's view and include in their record when and how it conflicts with your own.

### ***If information in a record is found to be factually inaccurate***

In paper records, in line with professional guidelines, you should keep the information in the record, but cross it out with a single line and add an entry to explain the problem and any consequences it may have.

If reports or results have been included in the wrong record, you should move these to the correct record and, if necessary, add a note to the record explaining what happened and where the report or results can be found if they are needed. You do, however, need to make sure that you maintain the confidentiality of the person whose information was wrongly filed.

The same principles apply to electronic records, and you should always add clear entries to identify the changes you have made.

There will be times when you are asked to completely remove some of the content of the record so that there is no trace that it was ever there, and we have explained in previous sections (page 8) why we feel that this should only be done in exceptional circumstances for paper records and not at all for electronic records. It is important that you discuss this fully with the patient or service user. You may also want to get advice from your Caldicott Guardian or, for healthcare, from your medical defence

organisation or another appropriate person.

Patients may not know that making changes to an electronic record leaves traces which cannot be completely removed. You may need to explain that this fact can protect your and their interests if a dispute arises and cannot be settled.

If you send information to records which are used by more than one organisation, it is good practice to have an agreed policy about how you will jointly manage amendments that are made to the records.

The approach above is emphasised in professional, regulatory and ethical guidance, all of which stress the importance of accurate information and good communication. Both the Medical Defence Union and the Medical Protection Society (who offer doctors advice and protection against claims) agree that where there is a dispute that cannot be settled, adding a note to the record which explains the dispute is the best way of dealing with the issue.



## Parents and young people

Our guidance applies to any record which fits our definition ('information related to the provision of health or social care which identifies the patient or service user personally'), whether the record relates to an adult or a child.

However, as children's use of our guidance will change as they grow up and become more able to make decisions for themselves, and children's records may contain information about their parents, we thought it appropriate to explain how our guidance will normally apply to children's records.

This is a complicated area. While we have done our best to explain the situation, there may be exceptional circumstances where the information which follows does not apply.

**Advice to parents** ('parents' includes all those people who have parental responsibility)

### 1 If your child is not able to understand and make decisions

You can see your child's record and ask for changes to be made to the record as explained in this guidance. This can be information about your child or about you as their parent. If the changes are felt to be in your child's best interest, they will be made.

### 2 If your child is felt capable of understanding and making decisions

a You can ask to see the information in your child's record, but your child will be asked for their agreement first. If you are allowed to see your child's record, you can ask for changes to be made to information about your child, as set out in our guidance, but they will be asked for their agreement.

b You can see and have changes made to the information about you in your

child's record. Your child will not be able to see this information without your agreement and you can hide this information from them.

## Advice to young people

Your record will contain information about you and might contain information about your parents.

- 1 If you are under the age of 16 and the person who keeps your record thinks that you are able to understand and make decisions, you can see your record. You will be shown your own information, but if there is any information in your record about your parents you cannot see this without their agreement.

Your parents can see any information about them in your record without your agreement. However, you will be asked for your agreement before your parents can see the information about you in your record.

- 2 You can ask for changes to be made to the information in your record which is about you, as we have explained in this guidance.
- 3 If your parents have given you permission to see the information about them in your record, you can ask for this to be changed, as explained in this guidance. However, your parents will be asked for their agreement first.

## Parents and young people

If you disagree about who can see the content of a record or ask for changes, your local council's social services department or your local hospital or GP practice will ask the advice of their Caldicott Guardian (a senior staff member who is responsible for protecting the privacy of patients and service users).

### *What the law and professional guidelines say about records*

In line with professional guidance and under their contract of employment (and sometimes the law), health and social care professionals must keep records. It is not possible or sensible to receive either healthcare or social care without some records being kept.

The Data Protection Act 1998 is the main relevant law. The Act refers to 'processing' data which covers collecting, storing, gaining access to, using or changing information.

The Act:

- gives people a legal right to see their records;
- makes it a requirement that any information held is accurate and, where appropriate, kept up to date;
- gives people the right to have factual inaccuracies in their records put right;
- can be used to ask that an opinion which is factually incorrect is changed or removed from a record (an opinion is not necessarily factually incorrect just because someone else, even another clinician or social worker, disagrees with it); and
- can be used to ask that information is not processed if it is causing significant unnecessary damage or distress.

The Act does **not**:

- give people the right to ask for professional opinions to be amended, unless they were based on factually incorrect information (or unless section 10 of the Data Protection Act is used - see page 13); or

- allow people to insist that their records are kept in one format rather than another (for example, paper rather than electronic). Also, it does not allow people to say where in the UK their records will be kept, other than that they must be stored securely.

Section 10 of the Data Protection Act allows a person to ask that an organisation stops processing information it holds about them, on the grounds that the processing is likely to cause that person significant unnecessary damage or distress. (The actual words used in the Act are 'substantial and unwarranted'.) However, this is a complicated part of the Act, and there are several circumstances where it does not apply. Requests made using section 10 must demonstrate why processing is causing unnecessary damage or distress and are considered case by case. There is more information on section 10 on page 13.

The Information Commissioner's Office have issued guidance (a 'Good Practice Note' - see note 6 on the following page) which confirms that the Data Protection Act 1998 covers any expression of opinion about an individual. However, it does not lay down specific rules about what should or should not be recorded as an opinion, other than it should be the minimum necessary for the purpose.

The guidance explains that opinions should not include irrelevant material. However, it also says that neither believing that an opinion contains irrelevant material, nor that an opinion has failed to take account of information which is believed to be important, are reasons for using the Data Protection Act 1998 as the basis for asking for an opinion to be removed from a record.

There is no law which deals directly with disagreements over professional opinions which are not factually incorrect.

The Access to Health Records Act 1990 (see note 7 below), which applied to records put together after 1 November 1991, gave patients the legal right to have a comment added to any entry in their health record that they disagreed with. This right was lost when the Act was replaced by the Data Protection Act 1998, which only deals with issues around factual inaccuracies. This difference was identified as the Data Protection Act 1998 was going through Parliament and the Department of Health agreed to issue guidance on adding comments to records.

At the time we produced this document, the Department of Health guidance advises clinicians to agree to add a comment to a record if the patient:

- asks for this; **and**
- has used the NHS complaints procedure; **and**
- has complained to the Information Commissioner.

We disagreed with this approach. We believe that patients should not have to make a formal complaint to get a comment added to their record. We have advised the Department of Health that it would be appropriate to revise its guidance on this and it has agreed to do this.

Both the Medical Defence Union and the Medical Protection Society advise that adding a note explaining the patient's concerns, or offering the patient the opportunity to add information to the records, is an appropriate way of dealing with any dispute over an opinion in a record and maintains good doctor-patient relationships.

### Notes

- 6 Information Commissioner's Office, 'Good Practice Note' - [www.ico.gov.uk/upload/documents/library/data\\_protection/practical\\_application/gpn\\_recording\\_and\\_retaining\\_professional\\_opinions%20v1\\_290408.pdf](http://www.ico.gov.uk/upload/documents/library/data_protection/practical_application/gpn_recording_and_retaining_professional_opinions%20v1_290408.pdf)
- 7 Access to Health Records Act 1990 - [www.opsi.gov.uk/acts/acts1990/ukpga\\_19900023\\_en\\_1](http://www.opsi.gov.uk/acts/acts1990/ukpga_19900023_en_1)

### *Members of the Working Group*

- Ian Hayes (Working Group Chair) - public member of the National Information Governance Board (NIGB).
- Dr Gillian Braunold - GP and Clinical Director for the Summary Care Record, NHS Connecting for Health.
- Dr Nick Clements - corresponding advisor of the NIGB, Medical Protection Society.
- Dr John Holden - corresponding advisor of the NIGB, Medical Defence Union. (The Medical Defence Union has not approved this document.)
- Rabbi Sylvia Rothschild - public member of the NIGB.
- Dr Michael Wilks - public member of the NIGB.

### *The members of the Working Group are very grateful for the help and support of those who provided evidence to them*

- The patients and members of the public, who provided very helpful evidence, both by email and in person, but asked for their details to remain confidential.
- Dr Stella Clark, Fife Primary Care Trust Medical Director and Caldicott Guardian.
- Dr Emyr Jones, Consultant Physician, Medical Director and Caldicott Guardian at Doncaster and Bassetlaw Hospitals NHS Foundation Trust.
- Dr Richard Fitton, GP and Caldicott Guardian at Hadfield Medical Centre, Glossop.
- Mr Stuart Dutfield and Mr Alan Hadfield for allowing the group to consider 'The Joy project', which was funded by a legacy in memory of Mrs Joy Dutfield.
- Johan Taylor, Practice Manager at Marple Cottage Surgery, Stockport.
- Dr Mary Hawking, GP at Kingsbury Court Surgery, Dunstable.
- Sarah Egleton, Head of Health Records, Norwich University Hospitals NHS Foundation Trust.
- A number of other healthcare professionals, who asked for their details to remain confidential to protect the identity of their patients.
- Penny Hill, NIGB Public member.

## *The Working Group's responsibilities*

### **Purpose**

- a To produce a report to the National Information Governance Board (NIGB), which will be made public, outlining the current position, identifying any improvements needed and making appropriate recommendations.
- b To produce the necessary advice and guidance for the NIGB, once the NIGB's recommendations have been accepted.

### **Context**

When carrying out its review, the Working Group will follow the principles the NIGB works to. This particularly includes giving people who use health and social care services appropriate control over, and access to, their own information. This is central to the role of the NIGB.

### **Exclusions**

The Working Group's responsibilities do not include dealing with:

- the records of patients who have died;
- disputes raised by a third party; and
- mistakes identified through a performance assessment or clinical audit.

The exclusions raise a number of different issues and may need to be considered further in the future.

### **Future work**

The Group will consider how the proposed guidance and principles for health records might apply to social care records.

### **Terms of reference**

- 1 To review the laws and professional guidelines related to disagreements over the content of clinical records.
- 2 To understand the issues associated with making changes to records or adding notes about the accuracy of information in records.
- 3 To understand the differences between paper and electronic records, and the consequences of using them.
- 4 To understand whether the NHS Care Records Service presents any opportunities or affords any difficulties in this area.
- 5 To gather the views of patients and clinicians to provide practical examples of this matter.
- 6 To consider whether corrections of mistakes should include information which has already been removed or which hides the identities of patients by failing to include names (for example, in the secondary uses service).
- 7 To consult the Information Commissioner's Office.
- 8 To involve the Information Standards Board in matters relating to the quality of information.

## References

### **Medical Defence Union advice on medical records and reports -**

[www.the-mdu.com/section\\_GPs\\_and\\_primary\\_care\\_professionals/topnav\\_Advice\\_centre\\_1/nav\\_Medical\\_records\\_and\\_reports\\_9.asp](http://www.the-mdu.com/section_GPs_and_primary_care_professionals/topnav_Advice_centre_1/nav_Medical_records_and_reports_9.asp)

### **Department of Health, Patient Confidentiality and Access to Records -**

[www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Patientconfidentialityandcaldicottguardians/index.htm](http://www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Patientconfidentialityandcaldicottguardians/index.htm)

### **NHS Care Records Service -**

[www.nhscarerecords.nhs.uk/what-is-the-nhs-crs](http://www.nhscarerecords.nhs.uk/what-is-the-nhs-crs)

### **GMC Guidance for Doctors on Confidentiality -**

[www.gmc-uk.org/static/documents/content/Confidentiality\\_core\\_2009.pdf](http://www.gmc-uk.org/static/documents/content/Confidentiality_core_2009.pdf)

### **Medical Ethics Today: Its Practice and Philosophy (2nd Revised edition)**

ISBN-10: 0727917447- BMJ Publishing Group. This contains guidance on removing information from health records.



This report can be downloaded from our website at:  
[www.nigb.nhs.uk](http://www.nigb.nhs.uk)



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