



BRIEFING PAPER

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Accessing and sharing health records and patient confidentiality

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Summary

Individuals have a right to access their own health records, and in limited circumstances, access to the records of other people. The Government has made a commitment that patients should gain access to their health records within 21 days following a request. Access to health records may also be granted in limited circumstances for relatives or in the case of deceased patients. This briefing describes how patients may request access to their records, and the circumstances in which access to the records of others may be allowed.

The Government has encouraged the NHS to make better use of technology, so that patients can manage their own healthcare needs, whilst ensuring that data remains safe at all times. As part of this, the Government has committed that all patients will have online access to personal medical records by 2016. This will include access to not only their own GP electronic records online in full, but also a summary of their allergies, medication, blood results, appointment records and medical histories. By 2018, this record will also include information from all the patient's health and care interactions.

Additionally, the NHS is introducing Summary Care Records - electronic health records of essential patient data - to enable healthcare staff across the country to provide immediate care and treatment. NHS England and the Health and Social Care Information Centre will also introduce the care.data programme, a national collection of anonymous patient data to enable population-level analysis of health trends. The national roll-out of care.data will begin once a pathfinder exercise has taken place.

The briefing also outlines safeguarding arrangements for confidential patient information. In 2013, a review was carried out by the National Data Guardian for health and care, Dame Fiona Caldicott, to ensure that there is an appropriate balance between the protection of patient information and the use and sharing of information to improve care. In September 2015, the Health Secretary commissioned the CQC to carry out a review into standards of data security for patients' confidential data across the NHS, for which the National Data Guardian will develop guidelines for data protection.

This briefing also describes statutory and public interest disclosures of patient information; information sharing rules for people who lack mental capacity; and access to information on hereditary conditions for relatives.

This briefing relates to patients in England.

1. Accessing and sharing patient health records

The Department of Health produced its [Guidance for Access to Health Records Requests](#) in 2010. This covers the pieces of legislation which govern access to patient health records:

The Data Protection Act 1998 – governs rights for living individuals to access their own records. The right can also be exercised by an authorised representative on the individual's behalf.

The Access to Health Records Act 1990 – governs rights of access to deceased patient health records by specified persons.

The Medical Reports Act 1988 – governs the right for individuals to have access to reports, relating to themselves, provided by medical practitioners for employment or insurance purposes¹

Under the *Data Protection Act 1998*, individuals have a right to access their own health records, and in limited circumstances, access to information about other people. The *Data Protection Act* extends equally to all relevant records relating to living individuals, including records held in the private health sector and health professionals' private practice records.

When an individual requests access to a health record, a "data controller", which could be a GP or the organisation that a health professional is employed by, is responsible for ascertaining the purpose of the request and the manner in which the information is supplied. An individual must request access to their health record in writing, or verbally if a written request is not possible.

The Government has made a commitment that health record requests should normally be handled within 21 days, although the *Data Protection Act* grants 40 days to comply.²

The release of a health record is subject to consultation with either:

- the health professional who is currently, or was most recently, responsible for the clinical care of the data subject in connection with the information which is the subject of the request; or
- where there is more than one such health professional, the health professional who is the most suitable to advise on the information which is the subject of the request.³

Requests for access for former UK citizens now living abroad should be treated in the same way as someone making an access request from within the UK. Hospital records are kept for a minimum of eight years

¹ Department of Health, [Guidance for Access to Health Records Requests](#), February 2010, page 8.

² Department of Health, [Guidance for Access to Health Records Requests](#), February 2010, page 10

³ Department of Health, [Guidance for Access to Health Records Requests](#), February 2010, page 11

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and GP records for a minimum of 10 years following treatment.⁴ NHS organisations should retain records in accordance with the retention schedules outlined in part 2 of the Department of Health [Records Management NHS Code of Practice](#) (2006).

1.1 Charges to access records

There are different fees to obtain a permanent copy of health records depending on how the information is stored. The maximum charges, including postage and package costs, are:

- £10 for records that are only held on computer,
- £50 for records that are only held manually, and
- £50 for records that are held partly on computer and partly manually⁵

If a patient simply wants to view their health records, instead of obtaining a copy, the maximum charge that can be levied is £10. This fee should be deducted from the charge for obtaining a copy if a patient later decides they wish to have a permanent record.

The *Data Protection Act* stipulates that fees for health records access should be paid in advance, but in order to provide a helpful service to patients, NHS organisations may request the fee when access to the record is given.

1.2 Limiting access to health records

There are certain circumstances in which full access to a patient's health records may be denied. These include cases where:

the information released may cause serious harm to the physical or mental health or condition of the patient, or any other person, or

access would disclose information relating to or provided by a third person who has not consented to that disclosure **unless**:

- The third party is a health professional who has compiled or contributed to the health records or who has been involved in the care of the patient.
- The third party, who is not a health professional, gives their consent to the disclosure of that information.
- It is reasonable to disclose without that third party's consent.

1.3 Providing information to relatives and carers

Normally, someone with parental responsibility for a child will have the right to apply to view the child's health records. However, health

⁴ NHS Choices, [How to manage and access your records - NHS Choices](#) [last accessed 16 December 2014]

⁵ Data Protection (Subject Access) (Fees and Miscellaneous Provisions) Regulations 2000

professionals must take into account their confidentiality duty when choosing whether to disclose this information.

For information about how patient confidentiality rules apply to other relatives and carers, see section 2.4 – Public interest disclosures of patient information.

1.4 Access to deceased patients' health records

The *Access to Health Records Act 1990* gives certain individuals rights to the health records of deceased patients, defined as 'the patient's personal representative and any person who may have a claim arising out of the patient's death'. A personal representative has unqualified access rights to the patients' health records, and individuals other than the personal representative have a legal right of access only if they have a claim resulting from a patient's death.⁶

There is a maximum charge of £10 to view a deceased patient's medical record. If an individual wishes to obtain a hard copy, there is no maximum charge but it should not result in a profit for the record holder.

For further information on patient confidentiality relating to deceased patients, see section 2.5 – Deceased patients.

1.5 Care.data

The *Health and Social Care Act 2012* introduced changes to allow the Health and Social Care Information Centre (HSCIC) to collect and share confidential information from health records. One of the key changes is a proposed electronic care.data service. This will extract and link large amounts of patient data collected as part of NHS care in order to improve the delivery of healthcare and to benefit researchers inside and outside the NHS.

The care.data programme was paused in February 2014, and a decision was taken to have a phased approach to implementation starting with a pathfinder stage. A full evaluation of the pathfinder stage will take place before national rollout of care.data begins. Six CCGs have been chosen as pathfinders (Blackburn with Darwen, Leeds North, Leeds West, Leeds South and East, West Hampshire and Somerset.)⁷ The pathfinder practices for the programme are planning to communicate with their patients in autumn 2015.⁸

The National Data Guardian for health and care, Dame Fiona Caldicott, will provide advice on the wording for a new model of consents and opt-outs to be used by the care.data programme. Care.data communications will not be issued until Dame Fiona Caldicott the

⁶ Department of Health, [Guidance for Access to Health Records Requests](#), February 2010, page 14

⁷ [PQ 7630 \[on General Practitioners\], 23 July 2015](#)

⁸ [PQ 7629 \[on Medical Records: Publicity\], 23 July 2015](#)

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National Data Guardian, has advised the Secretary of State that she is satisfied with the safeguards NHS England has put in place.

For background information, see the Library briefing on [Care.data](#) (March 2014).

1.6 Accessing records online

The Government's Information Strategy, [The Power of Information: Putting all of us in control of the health and care information we need](#), published in May 2012, set out the Government's ambition for a new approach to information and IT across health and care to enable more joined up, safer, better care. It set out the following objectives regarding individuals' access to their own medical records:

Increasingly, we will be able to interact with health and care services online, for example to book appointments or communicate electronically.

Letters from health and care professionals about our care need to be available electronically to us, and to other professionals involved in our care.

It will become normal for us to be able to access health and care services – including our own records – online.

Electronic access to our own care records where we request it will start with GP records by 2015 and our social care records as soon as IT systems allow. Work with patient, service user and professional bodies and with industry will enable this access to expand progressively to our records across health and care.

Increasingly, patients will be able to obtain personalised information on opportunities to improve their own health or manage the consequences of any illness.⁹

In December 2014, the Government mandated NHS England to ensure that all patients will have access to their medical records online by March 2015.¹⁰ NHS England said that in December 2014, 21% of patients in England could access their medical records online.¹¹

In response to a PQ, the Minister for Life Sciences, George Freeman, said that in April 2015 indicative data showed the total number of times a patient had accessed their record or a part of their record was 348,300.¹² However, this is the number of times that patients have accessed records which might include double counting - it's not the number of individual patients who are able to access their records.

In a speech on 2 September 2015, the Health Secretary outlined a vision for the use of technology across the NHS. He announced that patients will be able to access and interact with their GP online within 12 months. By 2016, all patients should be able to access their own GP

⁹ Department of Health, [The power of information: Putting all of us in control of the health and care information we need](#), May 2012

¹⁰ [HC Deb 13 Nov 2012, c179](#) and Department of Health, [A mandate from the Government to NHS England: April 2014 to March 2015](#), December 2014

¹¹ NHS England, [21% of patients in England can now access their medical record online](#), 8 December 2014 [last accessed 16 December 2014]

¹² [\(PQ 2528 \[on Medical records: internet\], 22 June 2015\)](#)

electronic record online in full, and see not just a summary of their allergies and medication but blood results, appointment records and medical histories. By 2018, this record will also include information from all the patient's health and care interactions.¹³

1.7 Summary Care Records

Patients' medical records are kept in the place where they receive care, such as a GP surgery. NHS Choices states that "These places can usually only share information from your records by letter, email, fax or phone. At times, this can slow down treatment and sometimes make it hard to access information."¹⁴

To address these challenges, the NHS is introducing Summary Care Records, which are electronic health records containing essential information about a patient, such as their medication, allergies and adverse reactions. This will enable healthcare staff across the country to provide direct care and treatment. It is being introduced across England. Patients can opt out of having a Summary Care Record.¹⁵

The NHS Connecting for Health website has a [FAQs section](#) that gives an overview of the records system, and there is a particular section on [Access to your records](#). Access to the Summary Care Record is restricted to medical staff and they should only look at the information they need to do their job:

Who can see my Summary Care Record?

Only NHS healthcare staff involved in supporting or providing your care can see your Summary Care Record. Healthcare staff who can see your Summary Care Record:

- need to be directly involved in caring for you;
- need to have an NHS Smartcard with a chip and passcode (like a bank card and PIN);
- will only see the information they need to do their job; and
- should have their details recorded.

Healthcare staff will ask your permission every time they need to look at your Summary Care Record. If they cannot ask you, for example if you are unconscious, they may look at your Summary Care Record without asking you. If they do this, they will make a note on your record to say why they have done so.

In July 2014, NHS England announced that 40 million patients in England now have an electronic Summary Care Record and access is being rolled out to A&E, NHS 111, and GP out-of-hours services.¹⁶ In September 2015, the Health Secretary said that by the end of 2018, all doctors and nurses will be able to access "the most up-to-date lifesaving information" across GP surgeries, ambulance services and

¹³ Department of Health and National Information Board, [Health Secretary outlines vision for use of technology across NHS](#), 2 September 2015

¹⁴ NHS Choices, [Your Records](#) [last accessed 20 March 2015]

¹⁵ For the opt-out process, see NHS Choices, [Introduction to Summary Care Records](#) [last accessed 19 December 2014]

¹⁶ NHS England, [Summary Care Record hits 40 million milestone](#), 31 July 2014 [last accessed 19 December 2014]

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A&E departments, no matter where the patient is in England. By 2020 this will include the social care system as well.¹⁷

NHS is also investigating whether community pharmacies should have access to Summary Care Records and whether this would improve existing practice and patients' experience.¹⁸

For further information, see the Library briefing on [Electronic Patient Records: the roll-out of the Summary Care Record](#).

¹⁷ Department of Health and National Information Board, [Health Secretary outlines vision for use of technology across NHS](#), 2 September 2015

¹⁸ [HC Deb 3 July 2014 c710W](#)

2. Sharing confidential patient information

This section details the current arrangements governing confidentiality of patient information.¹⁹

The NHS Constitution explains that patients have the right to privacy and confidentiality, to expect the NHS to keep patient confidential information safe and secure, and to be informed about how their information is used.

Patients also have the right to request that their confidential information is not used beyond their own care and treatment and to have their objections considered, and where their wishes cannot be followed, to be told the reasons, including the legal basis.

The Health and Social Care (Safety and Quality) Act 2015 amended the Health and Social Care Act 2012 to introduce a duty for health professionals to share patient information to facilitate the provision of health services or adult social care in England, in the individual's best interests. Further information can be found in the Library briefing on the Bill [here](#). The BMA opposed the Bill and said:

Health information sharing is governed by professional obligations to share relevant information for effective patient care, underpinned by patient consent. It is unnecessary to replace this with a statutory framework without clear justification as to why it is needed and which risks weakening confidentiality safeguards that currently apply.²⁰

2.1 Confidentiality and sharing health information

Patient information that is kept by health and social care providers must be securely safeguarded. Patient-doctor confidentiality is considered one of the cornerstones of medical practice, so that patients feel able to discuss sensitive information without fear of it being improperly disclosed. The British Medical Association's [Confidentiality and disclosure of health information tool kit](#) states that:

Confidentiality is an essential requirement for the preservation of trust between patients and health professionals and is subject to legal and ethical safeguards. Patients should be able to expect that information about their health which they give in confidence will be kept confidential unless there is a compelling reason why it should not.

In addition, individuals also expect that relevant health information is shared among their care team effectively and reliably, so as to ensure

¹⁹ The BMA provides a definition of confidential information in its [Confidentiality and disclosure of health information tool kit](#) – Card 2: General information.

²⁰ BMA, [Health and Social Care \(Safety and Quality\) Bill, House of Lords, Committee stage](#), 13 March 2015

high quality care, an integrated service and a better experience for patients.

Lastly, the sharing of anonymised patient information more widely can bring huge benefits to improving patient care. Tracking and analysis of patient health information allows health and social care to advance medical research and design more effective services. Information used in this way must be anonymised and untraceable to individuals before it is released for this purpose. The Health and Social Care Information Centre is responsible for ensuring that data is suitable for being used in this way.

The balance between the protection of patient information and the use and sharing of information to improve care was the subject of an Information Governance Review in 2013 led by the now National Data Guardian for health and care, Dame Fiona Caldicott.

The Caldicott Review – April 2013

A report by the NHS Future Forum in January 2012²¹ had found that information governance was being cited as a barrier to sharing information among health professionals, even when sharing information would have been in the patient's best interests. The Future Forum recommended an independent review "to ensure that there is an appropriate balance between the protection of patient information and the use and sharing of information to improve patient care".

The Government accepted this recommendation and asked Dame Fiona Caldicott²² to carry out such a review. [Information: To Share Or Not To Share? The Information Governance Review](#), was published in April 2013.

The Review set out seven revised principles to guide information governance – known as the 'Caldicott principles':

1. Justify the purpose(s)

Every proposed use or transfer of personal confidential data within or from an organisation should be clearly defined, scrutinised and documented, with continuing uses regularly reviewed, by an appropriate guardian.

2. Don't use personal confidential data unless it is absolutely necessary

Personal confidential data items should not be included unless it is essential for the specified purpose(s) of that flow. The need for patients to be identified should be considered at each stage of satisfying the purpose(s).

3. Use the minimum necessary personal confidential data

Where use of personal confidential data is considered to be essential, the inclusion of each individual item of data should be considered and justified so that the minimum amount of personal

²¹ [Information A report from the NHS Future Forum](#), 2012

²² In 1997, Dame Caldicott also carried out a [review of patient identifiable-information](#), which established fundamental principles about the way confidential patient information is handled.

confidential data is transferred or accessible as is necessary for a given function to be carried out.

4. Access to personal confidential data should be on a strict need-to-know basis

Only those individuals who need access to personal confidential data should have access to it, and they should only have access to the data items that they need to see. This may mean introducing access controls or splitting data flows where one data flow is used for several purposes.

5. Everyone with access to personal confidential data should be aware of their responsibilities

Action should be taken to ensure that those handling personal confidential data — both clinical and non-clinical staff — are made fully aware of their responsibilities and obligations to respect patient confidentiality.

6. Comply with the law

Every use of personal confidential data must be lawful. Someone in each organisation handling personal confidential data should be responsible for ensuring that the organisation complies with legal requirements.

7. The duty to share information can be as important as the duty to protect patient confidentiality.

Health and social care professionals should have the confidence to share information in the best interests of their patients within the framework set out by these principles. They should be supported by the policies of their employers, regulators and professional bodies.

The Caldicott Review also made 26 recommendations covering areas such as patients' access to all electronic care records about them; information sharing among an individual's care team; opting-out of information sharing; and breaches of information governance. The full list of recommendations can be found in [section 14 of the Review](#).

The Government published its [Response to the Caldicott Review](#) in September 2013, and accepted in principle each of the 26 recommendations. The Government's response outlined how these recommendations will be implemented, and includes key commitments for health and social care providers, NHS England and organisations such as the Care Quality Commission (CQC).

In September 2015, the Health Secretary announced that a new review of standards of data security for patients' confidential data across the NHS will be carried out by the CQC. The National Guardian for health and care, Dame Fiona Caldicott, will contribute to this review by developing clear guidelines for the protection of personal data against which every NHS and care organisation will be held to account.

2.2 Health and Social Care Information Centre (HSCIC) guidance on confidentiality

The HSCIC has a major role in implementing these recommendations. Under the *Health and Social Care Act 2012* the HSCIC also has a statutory duty to produce a Code of Practice for handling confidential information covering “the practice to be followed in relation to the collection, analysis, publication and other dissemination of confidential information concerning, or connected with the provision of health services or of adult social care in England”.

The HSCIC published [A guide to confidentiality in health and social care](#) in September 2013²³, which sets out the confidentiality rules that should be followed in care settings run by the NHS or publicly funded adult social care services. The guide was based on the Caldicott principles and incorporated the good practice recommended by the Information Governance Review.

The HSCIC guide set out five key principles for confidentiality:

- Confidential information about services users or patients should be treated confidentially and respectfully

- Members of a care team should share confidential information when it is needed for the safe and effective care of an individual

- Information that is shared for the benefit of the community should be anonymised

- An individual’s right to object to the sharing of confidential information about them should be respected

- Organisations should put policies, procedures and systems in place to ensure the confidentiality rules are followed

The review recommended that senior individuals are appointed to be responsible for following confidentiality procedures, coined “Caldicott Guardians”.

2.3 Legal and statutory disclosures of information

There are certain circumstances in which a health professional is required by law to disclose medical information, regardless of patients consent. Statutory disclosures are required under the following legislation – this is not an exhaustive list:

- Public Health (Control of Disease) Act 1984 and Public Health (Infectious Diseases) Regulations 1988 – a health professional must notify local authorities of the identity, sex and address of any person suspected of having a notifiable disease, including food poisoning

- Abortion Regulations 1991 – a doctor carrying out a termination of pregnancy must notify the Chief Medical Officer, giving a

²³ The guide is supported by a [references document](#) which provides more detailed information for organisations and examples of good practice.

reference number and the date of birth and postcode of the woman concerned

Reporting of Injuries, Diseases and Dangerous Occurrences Regulations 1985 – deaths, major injuries and accidents resulting in more than three days off work, certain diseases and dangerous occurrences must be reported

Additionally, some statutes allow, rather than mandate, disclosure of confidential information. For example, under the *Children Acts 1989*, disclosure is permitted to other organisations such as the police or social services if there is a suspicion that a child is suffering, or is at risk of suffering, significant harm.²⁴

In contrast, some statutes require health professionals to restrict disclosure of certain confidential information. For example, under the *Gender Recognition Act 2004*, it is an offence to disclose protected information such as a person's gender history after that person has changed gender. Also, the *NHS (Venereal Diseases) Regulations 1974* and the *NHS Trusts and PCTs (Sexually Transmitted Diseases) Directions 2000* (currently under review by the Department of Health) state that information capable of identifying a patient who is examined or treated for any sexually transmitted disease, including HIV, shall not be disclosed other than to health professionals in connection with their treatment or to prevent the spread of the disease.²⁵

Patient confidentiality can also be overridden under section 251 of the *NHS Act 2006*, which allows for the Secretary of State to set aside the duty of confidentiality for the purposes of research, audit and other medical purposes that are not directly related to a patient's care.²⁶

2.4 Public interest disclosures of patient information

There are also exceptional circumstances in which a health or social care professional may be obliged to share confidential patient information in line with the 'public interest'. The British Medical Association describes this type of mandatory disclosure:

Disclosures in the public interest based on the common law are made where disclosure is essential to prevent a serious and imminent threat to public health, national security, the life of the individual or a third party or to prevent or detect serious crime.

Informed consent from the individual must always be sought first, but an individual's right to confidentiality can be overruled to protect the public interest.²⁷

The HSCIC also provides guidance on sharing genetic information with family members, where the diagnosis of a condition in the patient might

²⁴ BMA, [Confidentiality and disclosure of health information tool kit](#) – Card 9: Legal and statutory disclosures

²⁵ BMA, [Confidentiality and disclosure of health information tool kit](#) – Card 12: Serious communicable diseases

²⁶ HSCIC, [A guide to confidentiality in health and social care](#), September 2013, page 21

²⁷ HSCIC, [A guide to confidentiality in health and social care](#), September 2013, page 20

point to the likelihood of the same condition in a blood relative. In circumstances where a patient refuses to give consent to share information, disclosure might still be justified in the public interest. The HSCIC recommends that:

Health and care professionals balance their duty to make the care of the patient their first concern against their duty to help protect the other person from serious harm. If practicable, health and care staff should not disclose the patient's identity in contacting and advising others of the risks they face.²⁸

2.5 Deceased patients

There is still an ethical obligation to respect a patient's confidentiality for deceased patients. The Information Tribunal in England and Wales has held that a duty of confidentiality applies to the health records of deceased patients under section 41 of the *Freedom of Information Act*. In Scotland, the *Freedom of Information Act* includes an exemption to the disclosure of deceased patients' medical records.²⁹

However, this confidentiality duty must be balanced with other interests, such as the wishes of people close to the deceased. The BMA recommends that doctors speak to their patients about possible disclosure of health information after their death, if there is likely to be sensitivity resulting from this.

There are however statutory rights to accessing medical records of deceased patients. Under the *Access to Health Records Act 1990*, unless a patient has expressly requested confidentiality after the death, a personal representative or someone who may have a claim as a result of a patient's death has a right of access to information specifically relevant to the claim, as described above.³⁰ However, disclosure may not take place if there is a risk of serious harm to an individual, or if there is information relating to another person.

2.6 Assessment of capacity to give or withhold consent

All patients aged 16 and over are presumed, in law, to have the capacity to either give or withhold their consent to disclosure of confidential information, unless there is evidence that indicates otherwise. For people under 16 in England, Wales and Northern Ireland, individuals under 16 must demonstrate they have a sufficient understanding of what is proposed in order to be said to have capacity. In Scotland, all children over 12 are deemed to have this capacity.³¹

²⁸ HSCIC, [A guide to confidentiality in health and social care: references](#), page 25

²⁹ BMA, [Confidentiality and disclosure of health information tool kit](#) – Card 11: Deceased patients

³⁰ BMA, [Confidentiality and disclosure of health information tool kit](#) – Card 11: Deceased patients

³¹ BMA, [Confidentiality and disclosure of health information tool kit](#) – Card 8: Children and young people

If a patient lacks capacity, medical information may need to be shared with relatives, friends and carers to enable health professionals to determine their best interests. The BMA states that:

Where a patient is seriously ill and lacks capacity, it would be unreasonable always to refuse to provide any information to those close to the patient on the basis that the patient has not given explicit consent. This does not, however, mean that all information should be routinely shared, and where the information is sensitive, a judgement will be needed about how much information the patient is likely to want to be shared, and with whom. Where there is evidence that the patient did not want information shared, this must be respected.³²

Patients who may have a mental health condition do not automatically lack this capacity. However, under the *Mental Health Act 1983*, qualifying patients are entitled to support from an Independent Mental Health Advocate (IMHA). Subject to certain criteria, section 130B of that Act provides that, in order to provide help to a qualifying patient, IMHAs may require the production of and inspect any records relating to the patient's detention or treatment in any hospital or to any after-care services provided for the patient under section 117 of the Act.³³

³² BMA, [Confidentiality and disclosure of health information tool kit](#) – Card 7: Adults who lack capacity

³³ [Code of Practice: Mental Health Act 1983](#), Chapter 20

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