

Core Ethics Guidance



How to approach an ethical question



The doctor-patient relationship



Consent and refusal by adults with decision-making capacity



Mental capacity



Children and young people



Confidentiality

British Medical Association Core Ethics Guidance

Introduction

The BMA has produced an ethics handbook since 1949, although their format and content have changed considerably, each reflecting the needs of doctors at the time. The last edition was 920-pages, published in 2012 (*Medical Ethics Today: the BMA's handbook of ethics and law, 3rd edition*) covering both practical guidance on day-to-day issues, and information about broader policy debates within medical ethics. It received positive reviews and feedback, but became out of date quite quickly and its circulation was limited; it was not accessible on the ward in the middle of the night when guidance might be needed. We have therefore thought carefully about how we can best provide the up-to-date information our members need, as and when they need it.

As a result, this latest version is quite different from its predecessors. First, it is available solely as an online resource, making it more accessible – at any time and from anywhere – and easier to update as and when new information becomes available. The content has also changed, now focussing exclusively on the practical issues and challenges doctors commonly face. The guidance is based on the type of questions we are asked by members, through our confidential ethics advice service, and information obtained from our monitoring of new legal cases, legislation, and guidance. As always, our guidance is designed for doctors across the UK, reflecting the legal and organisational differences between the four nations of the United Kingdom.

This guidance

The Medical Ethics Committee (MEC) produces a wide range of practical guidance and toolkits on specific topics (all available at www.bma.org.uk/ethics). This new resource brings together the core pieces of this guidance into a single document. It explains the BMA's step-by-step methodology for breaking down challenging ethical questions; identifying the relevant factors to consider; and then critically analysing them to reach ethically robust and logically argued solutions. Alongside this decision-making framework, the BMA's core ethics toolkits provide information on the legal and ethical aspects of the most common ethical question that arise in doctors' day-to-day practice. All this information is compiled into a single document with a simple, easy to remember URL (www.bma.org.uk/core-ethics). Links are also provided to additional ethics guidance on specific topics, making it quick and easy to find the information required.

The purpose of the BMA's guidance is not to provide definitive answers for every situation but to identify the key factors that need to be considered when decisions are made; to summarise the relevant legal considerations; and to signpost other key documents, such as guidance from the General Medical Council, including the latest versions of *Good Medical Practice*, and its more detailed guidance, which came into effect on 30 January 2024.

Our guidance sets out doctors' legal and professional obligations and reflects best practice. We acknowledge, however, that, despite their best efforts, doctors cannot always provide the level, and quality, of care they want to, because of the current state of the NHS and the pressures on healthcare professionals from staff shortages and lack of resources. GMC guidance sets out the principles of good practice and professional standards expected of all doctors registered in the UK. They provide a framework within which doctors must exercise their own professional judgement. All doctors must be aware of and follow the guidance and those who do not meet the standards set out by the GMC risk complaint and potentially regulatory action. In its guidance,

British Medical Association Core Ethics Guidance

the GMC uses 'must' to reflect a legal or ethical duty doctors are expected to meet (or be able to justify why they did not) and 'should' to refer to duties or principles that either may not apply to all doctors, or all situations, or where they recognise that doctors may not be able to comply due to factors outside their control. Where GMC guidance expects action that we believe may be very difficult for doctors to achieve in practice, we advise our members to take what steps they can to follow the guidance but, where that is simply not possible, that fact, and the steps taken, should be recorded in the medical record. Where appropriate, the difficulties encountered should be raised with management who have a responsibility to assist staff to meet their professional obligations. Where we are aware of specific difficulties doctors face, we have raised these with the GMC and will continue to do so.

The BMA's Medical Ethics Committee

Providing advice and guidance for members, is one part of the role of the BMA's Medical Ethics Committee. With the support of the specialist staff in the BMA's medical ethics and human rights team, the Committee also monitors legal developments to identify cases that are likely to have a significant impact on clinical practice. In addition to ensuring that our members are aware of any changes arising out of these cases, the MEC occasionally advises that the BMA should intervene in a particular legal case on behalf of our members. One such example is the case of McCulloch v Forth Valley Health Board which concerned the amount of information doctors are required to provide to patients when seeking consent. The Supreme Court dismissed the appeal, quoting from the BMA's submissions in its judgment but, if the case had been successful, it would have had a very significant impact on the working lives of our members.

The Medical Ethics Committee also continues to monitor and debate policy issues in medical ethics. Information about the topics the MEC has considered can be found on the <u>committee pages</u> of the BMA website. More detailed information on specific policy issues can also be found on the BMA website; for example, we provide detailed briefing materials on the current debates on physician-assisted dying (<u>www.bma.org.uk/pad</u>).

An important, but distinct, role of the Medical Ethics Committee is to take forward the BMA's work on <u>health and human rights</u>, speaking out against abuses of health-related human rights on a global stage.

Ten BMA members are elected onto the MEC each year; BMA members who are interested in standing for election to the Medical Ethics Committee can find more information here.

Core Ethics Guidance

	1. How to approach an ethical questic	<u>)n5</u>
	2. The doctor-patient relationship	<u>11</u>
	3. Consent and refusal by adults with decision-making capacity	<u>57</u>
O O	4. Mental Capacity Act - England and Wales	<u>76</u>
	5. Mental capacity in Northern Ireland	113
	6. Adults with Incapacity Scotland	144
	7. Children and young people	<u>175</u>
2	8. Confidentiality	<u>205</u>
	Additional BMA ethics and human rights guidance and resources	<u>239</u>

How to approach an ethical question



1

How to approach an ethical question

Approaches to ethical questions will vary depending upon the complexity of the question. Some can be easily resolved by reference to relevant law or regulatory guidance. Questions such as who can consent on behalf of a young child, for example, have well-established answers. The law sets the limits within which doctors may exercise their professional judgement. Guidance from the General Medical Council (GMC), which is binding on all doctors, must also guide doctors' actions. Within those parameters, however, doctors must use their judgement to make decisions that are reasonable in the circumstances and can be justified with sound and logical arguments.

Complex cases, particularly where duties to different parties conflict, require more detailed consideration. Through many years of providing ethical guidance for doctors facing real-life ethical challenges, we have developed a flexible approach to these dilemmas, combining practicality, law (UK-wide and devolved), and ethical reasoning. While there is no single 'right' way to tackle complex ethical questions, our approach recognises that ethical decision-making in medicine involves balancing a range of clinical, legal, regulatory, and practical issues to achieve the best available outcome.

For these more complex questions, we take the following six-step approach.

Step one: recognise that you are facing an ethical question

This is not always as easy as it sounds. The distinction between an ethical problem and a clinical or practical problem may not be clear cut, particularly in high-pressured work environments or where there are established cultures and practices. Ethical problems generally arise where there is a conflict of principles, values, rights, or interests, or where there are good moral reasons to act in two or more different ways, each of which may also be, in some way, morally flawed.

Sometimes the language we use suggests the problem may be an ethical one. Technical questions will often use words like 'can we' or 'can't we', in the technical sense of 'do we have the ability?'. Similarly, questions of medical law are also usually framed in terms of 'can we' or 'can't we', in the sense of 'is it lawful to do this?'. Ethical questions often involve words like 'should we' or 'shouldn't we', 'ought we' or 'oughtn't we'. We often ask ourselves if the decision is 'right' or 'wrong'. Consider, for example, a patient in a serious prolonged disorder of consciousness. On the clinical, technical side is the question of whether we can keep them alive in such a condition - and generally, we can. But then the question arises as to whether we should keep them alive. And this is now an ethical question. Not whether we can keep them alive, but whether it is right or wrong to do so.

Identifying a situation as raising an ethical problem, signals the need to stop and think through how best to proceed.

Step two: identify the ethically important components

Ethical questions in medicine can be complex. An important early step is to remove extraneous detail so the ethical question can be seen as clearly as possible. Before deciding on a response, it is vital to properly understand the question. This usually involves identifying relevant rights, duties, interests, benefits, and harms, along with all relevant viewpoints; particularly the views of the patient.



It can be helpful to start off by identifying the ethical concepts at play — is the question, for example, primarily about consent, mental capacity, or confidentiality? We can then go back to first principles to see if they help us address the question. For example, personal health information should remain confidential unless the patient consents to disclosure, there is a legal requirement to disclose, or there is an overriding public interest. This process can help to focus on the question that needs addressing and provide some indication of how to respond.

Where there are competing rights or interests, these need to be clearly articulated so that they can be assessed and prioritised. In some cases, it will be clear whose interests should take priority and the issue can be easily resolved. In child protection cases, for example, the rights and interests of children usually take priority over any adults involved and this can be a powerful aid to decision making.

Step three: where necessary, seek additional information

For some questions, identifying the ethically important components will be insufficient and further information may be required. Obtaining clarity about the relevant facts is an important part of the decision-making process. Where, for example, the question has to do with disclosing confidential information relating to a child, the child's decision-making capacity will need to be identified (or, if the child is very young, it will be important to know who has parental responsibility). Ethically, the patient is at the centre of decision making, and, in most cases, the informed views of the patient will be determinative. Even where a patient lacks capacity it is essential to take all reasonable steps to identify their prior wishes, feelings, and beliefs where relevant to the decision.

Part of this process of information gathering may involve speaking to other healthcare professionals who are involved in the patient's care, who may have a different perspective, or may have had more contact with the patient and, as a result, have additional information to feed into the process.

Step four: identify any relevant legal or professional guidance

Many ethical questions in medicine are addressed either directly or indirectly by GMC guidance and the law. For some questions this will provide a straightforward answer — the GMC makes it clear, for example, that doctors must not accept payments from providers to whom they refer patients. Other issues are more complex and may require advice from a range of sources. In addition to statute, case law, and GMC guidance, this could include advice from professional bodies such as the BMA, medical defence organisations, or relevant regulatory bodies such as the Human Tissue Authority. The law and GMC guidance are binding on doctors; professional guidance, such as that from the BMA or medical defence organisations, is not, but can provide useful insight and can help to identify actions that would, or would not, be considered reasonable. A decision that is in line with relevant and appropriate professional guidance is also less likely to be challenged.

Step five: critically analyse the question

For complex moral questions, this is often the challenging part. Where law, regulation, guidance — or discussion with informed colleagues — does not find a way forward, some form of critical analysis is required. Doctors do not need to be moral philosophers. The important point is that any decision is reasonable and defensible in the circumstances. In medicine, some decisions also need to be made urgently, without the luxury of extended consultation.



Critical analysis will ordinarily involve several considerations. Even where the law or guidance doesn't show a clear way forward, it may give an indication of things that must be considered. Critical analysis will also involve consideration of the morally relevant factors identified at step two. Where one or more of these compete, they need to be weighted to find which should take priority.

Consider a request from the police for full access to the medical records of a patient who is suspected of having committed a crime. Here duties of confidentiality to the patient are in tension with duties to the public good. Confronted with such a request, factors to consider will include:

- Is it possible to seek the patient's consent, bearing in mind that it may jeopardise the police investigation?
- Is the crime sufficiently serious to override duties of confidentiality?
- Is anybody else at risk of serious harm?
- What is the purpose of the disclosure and what information is required to assist the police?
- Can the information be obtained without breaching confidentiality?
- Is there an urgent need to disclose?
- If a disclosure is justified, what is the minimum information necessary to achieve the objective?

Based on an assessment of these, and any other relevant factors, the doctor must balance the competing interests and duties to make a judgement about whether breaching confidentiality is justified. Going through this process helps to provide the logical basis for the judgement reached which should be recorded in the medical record.

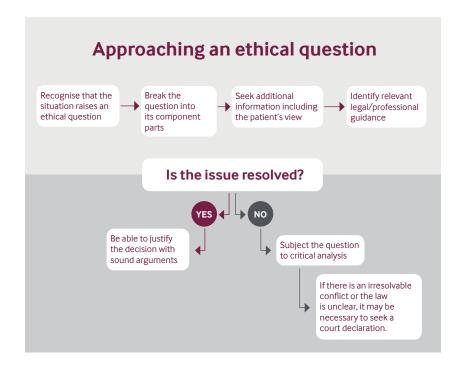
Step six: support the decision with sound arguments

It can always be helpful to discuss the issue, without breaching confidentiality, with a colleague, clinical ethics committee, or someone from the BMA or a defence body. Ultimately however, the doctor providing care must make the decision, working in partnership with the patient as far as possible. Doctors need to be able to justify their decisions and explain the reasoning behind them. This will include details of any discussion with the patient, those close to them, colleagues, or any professional adviser, along with any published professional guidance referred to. Where for example a patient refuses treatment necessary to prolong their life, and there may be doubts as to their capacity to make that decision, a written record should be kept of a formal assessment of their capacity. A record of information given to the patient — and those close to them where necessary — including information as to the likely consequences of their decision, should also be made.

Where the decision is serious, and a reasonable, consensual way forward cannot be found, or where the law is unclear, it may be necessary to seek a court declaration.

The BMA has an ethics advice service that is available and free to doctors and medical students in the UK. It can be accessed via support@bma.org.uk





Using the BMA's approach: should I disclose information about a serious transmissible disease?

You are a GP. A male patient tells you he has been to a private clinic for HIV testing and the result has come back positive. His partner is also registered at the practice. During the consultation you discuss the risk to his partner and begin to explore the importance of informing her of the result, its implications for her, and options for safer sex. During the conversation it becomes clear that your patient does not believe in any form of barrier contraception, is continuing to have sex with his partner and that they will shortly be trying for a child. He makes it clear that he has no intention of informing her. You suggest to him that you would like to discuss the issue with her directly, but he refuses.

What makes this an ethical problem? Doctors are aware that they owe their patients a duty of confidentiality. Ordinarily, doctors are under an obligation to respect patients' privacy and only disclose information where the patient agrees to it or where it is essential for their healthcare. Not only that, but this patient has explicitly refused consent to disclosure of information to his partner. On the other hand, your patient is putting his partner at a clear risk of serious harm, a harm that you could protect her from. It is this tension between two obligations that makes this a clear ethical problem.

In terms of the ethical concepts at play here, confidentiality is obviously important. What is the duty of confidentiality and what are its limits? But there is also his partner's right to be protected from serious, identifiable harm. Her interests are in tension with his rights to confidentiality. You have already sought consent from your patient to disclose information to his partner, but he has refused. Having identified the ethical problem, and the relevant conflicts in play, what are the next steps?



Confidentiality is an issue that regularly generates ethical challenges. The GMC, and professional bodies such as the BMA, all produce guidance for doctors in this area. The GMC has specific guidance on Confidentiality: disclosing information about serious communicable diseases. Although the guidance refers to a range of scenarios, it addresses our question explicitly:

You may disclose information to a person who has close contact with a patient who has a serious communicable disease if you have reason to think that:

- a. the person is at risk of infection that is likely to result in serious harm
- b. the patient has not informed them and cannot be persuaded to do so.'

Although this addresses our question directly, the GMC makes it clear that this is an example of a 'public interest' justification for the disclosure of confidential information. These arise where the public interest in the disclosure of information is stronger, or 'trumps', the duty of confidentiality. Although the GMC gives us a clear decision here, there will be occasions when the answer is less obvious and there is no clear answer. In these cases, we will have to engage in ethical reasoning, weighing up the different interests. In its guidance on public interest disclosures the GMC says:

'When deciding whether the public interest in disclosing information outweighs the patient's and the public interest in keeping the information confidential, you must consider:

- a. the potential harm or distress to the patient arising from the disclosure –
 for example, in terms of their future engagement with treatment and their
 overall health
- the potential harm to trust in doctors generally for example, if it is widely perceived that doctors will readily disclose information about patients without consent
- c. the potential harm to others (whether to a specific person or people, or to the public more broadly) if the information is not disclosed
- d. the potential benefits to an individual or to society arising from the release of the information
- e. the nature of the information to be disclosed, and any views expressed by the patient
- f. whether the harms can be avoided or benefits gained without breaching the patient's privacy or, if not, what is the minimum intrusion.

If you consider that failure to disclose the information would leave individuals or society exposed to a risk so serious that it outweighs the patient's and the public interest in maintaining confidentiality, you should disclose relevant information promptly to an appropriate person or authority.'

What the GMC requires here is the identification of all morally-relevant factors and a reasoned weighing and balancing of them. It would also be important to make a note of the decision, any advice taken, and the reasons behind the decision you made.



2

The doctor-patient relationship



Contents

2.1 The doctor-patient relationship	<u>13</u>
Key principles	13
The duty of care	
Delegation and referral	
2.2 Patient autonomy and choice	17
Patient choice	
Refusal or rejection of medical advice	19
Combining NHS and private care	20
2.3 Communication and honesty	23
Communicating with patients	23
Communicating with colleagues	26
Honesty, openness, and truth-telling	27
2.4 Maintaining professional boundaries	
Personal relationships	
Treating colleagues, friends, and family	
Gifts and bequests	33
O F Touch on described as an est	25
2.5 Trust and mutual respect	
Video and audio recordings	
Covert medication	
Change of interests	
Chaperones	30
2.6 Conscientious objection and expressing personal b	neliefs 39
Rights and limits to conscientious objection	
Responsibilities of those with a conscientious objection	
Expressing personal beliefs	
2.7 Care at a distance	43
High-level principles	
Deciding between remote or face-to-face consultations	
Prescribing remotely	
2.8 Doctors' responsibilities	46
Doctors' health and healthcare	46
Concerns about colleagues	48
2.9 Patients' responsibilities	
Patients' responsibilities	
Engagement with their health and healthcare	
<u>Patients who demonstrate violent, aggressive or racist behaviou</u>	<u> 1750</u>
2.10 Breakdown of the doctor-patient relationship	
Managing a breakdown in the doctor-patient relationship	53
2.11 Non-typical relationships and dual chligations	
2.11 Non-typical relationships and dual obligations	
Access to Medical Reports	
MULIUSIUS AUDI ADDISATIONS	



The doctor-patient relationship

Modern medicine is complex and dynamic. Although highly specialised, technologically sophisticated and often delivered by multi-disciplinary teams, strong doctor-patient relationships are at the heart of good care. Good therapeutic relationships, whether face-to-face or remote, are characterised by partnerships between doctors and patients. Patients increasingly seek to play an active part in their care, to understand the options available to them and to make the best health-promoting choices available. Doctors seek to explore what matters to individual patients, to provide them with the best available information, to act as advocates when needed, and to help them make choices that maximise their wellbeing in ways they are comfortable with. Good doctor-patient relationships are characterised by mutual respect, open and honest communication, and respect for the privacy, dignity and choices of patients.

Key principles

Healthcare professionals are among the most trusted and respected groups in society. Patients and the general public greatly appreciate what they do, in often challenging circumstances. The onus is principally on the healthcare professional to make contact with patients work well (although patients also have some responsibilities – see section 2.9), and to speak out when there is a risk of harm. The following basic principles underpin the doctor-patient relationship.

- Although doctors and patients both have obligations to treat each other with honesty and respect, doctors have particular duties to patients rooted in their professional status.
- Doctors must make the care of patients their first concern.
- Good communication requires openness, honesty and an ability to listen from both parties.
- Good patient care is person-centred, taking into account the patient as a whole person.

Do doctors and patients have different obligations?

Yes. As professionals, doctors are subject to specific duties rooted in their professional roles. While doctors and patients should both be honest in their communication and respectful in their dealings with each other, doctors have specific, patient-focussed duties. These duties prioritise the interests of patients. Key patient-facing principles are set out by the General Medical Council (GMC) in its guidance *Good medical practice* and include binding obligations on doctors to:

- make the care of patients their first concern;
- respect every patient's dignity and treat them as an individual;
- listen to patients and work in partnership with them, supporting them to make informed decisions about their care;
- protect patients' personal information from improper disclosure;
- act with honesty and integrity, and be open if things go wrong;
- protect and promote the health of patients and the public;
- never unfairly discriminate against patients or colleagues; and
- never abuse patients' trust in you or the public's trust in your profession.



What is patient-centred care?

Good medical care is patient-centred. This means that doctors take a 'whole person' approach to the care of their patients. Rather than focussing on specific needs or pathologies, a patient-centred approach addresses patients as individuals, sees them 'in-the-round', and pays particular attention to their individual values and circumstances, as well as their specific health and health-related needs. Patient-centred care prioritises the dignity of individual patients and is characterised by compassion and respect. It seeks to help people take control of their own health and care to enable them to live independent lives. Patient-centred care also involves doctors ensuring that care and treatment are coordinated as well as personalised. Patient-centred care involves doctors and patients working together to:

- identify the patient's health needs;
- understand what is important to the individual;
- make informed decisions about the patient's care and treatment; and
- support the patient to make healthcare decisions in line with their needs, values and priorities.

The duty of care

Do doctors have a legal as well as an ethical duty of care?

Yes. A duty of care is both an ethical, legal, and professional obligation to safeguard and promote the health and wellbeing of patients whilst they are in their care. This means acting in the best interests of patients, and not acting, or failing to act, in a way that causes harm. Healthcare professionals must also ensure that they act within their abilities, and not seek to provide care that lies beyond their level of competence — unless it is an emergency, no other appropriately qualified healthcare professional is available, and they have a reasonable belief that they can improve the outcome for the individual patient.

In a health service that is under immense pressure, with severe staff shortages, it is becoming increasingly common for doctors to be put in situations where they are required to act at the limits of their competence. If nobody else is available to provide urgent medical care, doctors must do the best they can in the circumstances, using the skills they have but should report such incidences to their managers, explaining the situation, that nobody else was available to provide care and what treatment was provided. Where these situations become part of everyday practice, rather than one-off incidences, potentially causing patient safety, dignity or comfort to be compromised, the matter should be raised urgently with senior management in secondary care or, in general practice, with appropriate organisations, for example, Care Quality Commission (CQC) and local Integrated Care Board (ICB). The BMA has guidance for consultants working in a system under pressure (see key resources) which may also provide a helpful steer for other healthcare professionals.

What is the legal duty of care?

The law imposes a duty of care on a healthcare professional in situations where it is 'reasonably foreseeable' that they might cause harm to patients through their actions or omissions. To discharge this legal duty, healthcare professionals must act in accordance with the broadly accepted standard of care. This is generally assessed as the standard to be expected of an 'ordinarily competent practitioner' performing that particular task or role. Failure to discharge the duty to this standard may be regarded as negligence. The legal test of negligence is known as 'the Bolam test' (based on the case of Bolam as modified by the case of Bolitho). As above, where, due to systemic problems, it is not possible to provide safe and appropriate care,



this should be reported to senior management in secondary care, or, in general practice, appropriate authorities, for example, CQC and local ICB.

When does the duty of care begin?

A duty of care to individual patients can vary depending on the type and duration of the professional relationship with them. Some healthcare professionals only see an individual once for a specific purpose, such as writing a report or assessing eligibility for a social benefit (see section 2.11 on non-typical relationships and dual obligations). Such encounters are generally transitory and, although they still involve some obligations to the person being examined, rarely involve an ongoing duty of care. When a therapeutic relationship exists, the situation is different; the duty of care can start even before a patient is seen. Legally, healthcare professionals have a duty of care when they assume some responsibility for a patient, such as when a patient is added to a general practice list. In secondary care, it may be on admission to a ward, acceptance onto a caseload, or once registered at an accident and emergency department.

How long does the duty of care last?

The duty of care begins when a doctor or other healthcare professional first engages with a patient and continues until one or other party ends the relationship. This can be when the patient moves from the area, is discharged after treatment, or transfers to another practitioner, for example because the relationship has broken down (see section 2.10 on the breakdown of the doctor-patient relationship). Some duties to the patient, mainly those related to confidentiality, extend beyond that person's death. The BMA's confidentiality toolkit provides more detail on this issue – see key resources.

Do doctors have a duty to try to contact patients who miss important appointments?

Questions are sometimes asked whether doctors have a duty to try to contact patients who fail to return following an initial consultation concerning a serious health matter, or who discharge themselves from hospital contrary to medical advice. Patients with the requisite capacity have a right to refuse treatment, including not returning for essential follow up or to receive the results of a test. Likewise, patients with the necessary capacity are entitled to decline any further treatment. Doctors should, however, make reasonable efforts to inform them as to the likely consequences of their decision. A balance needs to be struck between encouraging them to protect their health, where they appear willing to do so, and respecting their right to refuse (see section 2.2 for more information about situations where a doctor disagrees with a patient's decision).

Where patients simply do not turn up for essential treatment or follow up, doctors should make reasonable efforts to contact them, keeping in mind their duties of confidentiality. Hospitals should take responsibility for contacting patients who miss appointments, copying any correspondence to the patient's GP. There is not usually a duty on doctors to make further attempts to contact adults with capacity about non-attendance, although they may need to communicate with the patient, their parents or carers, or consider making a safeguarding referral, if they are aware that there is a child or vulnerable person involved and they have concerns about their safety and welfare.

If there are reasons why contacting a patient at home may be difficult, for example a young person seeking sexual health services or someone who is a victim of domestic violence, it may be helpful to have discussions in advance to ascertain how they wish to be contacted and note this on the medical record.



Delegation and referral

What are the responsibilities for the delegation of care, and referral of patients?

Delegation involves asking other staff to carry out procedures or provide care on your behalf. When a healthcare professional delegates specific tasks to someone less qualified, the professional arranging the delegation still retains responsibility for the patient's overall management and must ensure that tasks are delegated only to those who are competent to carry them out. In many cases hospital doctors ask GPs to monitor or prescribe as part of a patient's ongoing care; this is different to delegation and in most cases responsibility will either be transferred to the GP or it will be part of a shared care arrangement.

Referrals are usually made to someone with more specialised knowledge to carry out specific procedures, tests, or treatment that fall outside the sphere of competence, or of usual practice, of the referring professional. Referrals are usually made to another registered healthcare professional. If this is not the case, the person making the referral should ensure that the professional to whom the patient is referred is accountable to a statutory regulatory body or that systems are in place to assure the safety and quality of care provided.

The GMC's guidance on *Delegation and referral* at paragraphs 19-23 states:

- '19. The following paragraphs apply whether you are delegating or referring.
- 20. You should explain to the patient that another colleague or service will provide part or all of their care and explain the reasons why.
- 21. You must pass on to the medical, health, or social care professional or service provider involved:
 - a. relevant information about the patient's condition and history
 - b. the purpose of transferring care and/or the investigation, care or treatment the patient needs.
- 22. You should check that the patient understands what information you will pass on and why. If the patient objects to a disclosure of information about them that you consider essential to the safe provision of care, you should explain that you can't refer them or arrange for their treatment without also disclosing that information. You must follow paragraphs 26–33 of Confidentiality: good practice in handling patient information.
- 23. You must record your work in line with paragraphs 69–71 of *Good medical practice* and use the systems available to you effectively, particularly when you will not see the patient again.'



Key resources

BMA – Confidentiality toolkit

BMA – Guidance for consultants working in a system under pressure

GMC – Delegation and referral

GMC - Good Medical Practice

The Health Foundation – Person-Centred Care Made Simple



Patient autonomy and choice

Listening to patients and respecting their autonomy is a key ethical principle. Many patients wish to be active participants in their own healthcare and to be involved in creating and managing their health strategy and use of services. In most cases this is straightforward, and appropriate treatment options can be aligned with the patient's preferences. However, ethical dilemmas can arise when a patient disagrees with the advice given by healthcare professionals or requests alternative treatment and care.

Patient choice

Can patients choose where to receive care?

Some patients would like more say about where and who provides care, and they may have increased expectations due to, for example, the NHS Constitution in England, which emphasises their right to make choices about their NHS care and to receive information to support these choices. However, in practice these choices are limited. According to the NHS constitution, patients in England have the right to:

- choose their GP surgery, unless there are reasonable grounds to refuse (for example, they live outside the area that the surgery covers or a GP's list is closed); and
- for their first appointment, choose which provider, and team within that provider, to be referred to from all those who have a contract to provide the service (this can include private providers of NHS services).

There are some exceptions that may limit patient choice, for example patients cannot choose when and what services to use in cases where speed of access to treatment is particularly important, such as emergency services, cancer services, mental health services, and maternity services. In addition, people held under mental health legislation, military personnel, and prisoners (including prisoners on temporary release) cannot choose where to receive treatment.

Patients registered with a GP in Wales do not have a statutory right to choose at which hospital they receive treatment. NHS Wales does not operate a patient choice system but looks to provide services close to a patient's home where possible. However, patients on the border who are registered with a GP in England are entitled to exercise patient choice as outlined above.

Similarly, patients in Scotland and Northern Ireland do not have a statutory right to choose which NHS service they use.

Can patients choose which healthcare professional provides care?

For reasons of dignity, specific cultural traditions, or the intimate nature of the examination, some patients may request to see and be treated by a member of their own gender. Where it is feasible to do so, reasonable patient preferences should be respected, but there is no legal requirement for the NHS to provide a healthcare professional of the same gender in any healthcare setting.

Similarly, there may be specific reasons why complying with a patient's request to see a doctor of the same ethnicity, culture, or religion may provide clinical benefit. Nevertheless, patients cannot insist on seeing healthcare professionals from a specific racial, cultural, or religious background, and any such requests which are based purely on unlawful discrimination, with no clinical benefit, should be refused.



NHS bodies have obligations to provide competent, appropriately trained professionals but must not use racist or discriminatory criteria in their employment or referral practices. The NHS will not support racial or any other form of unfair discrimination. Private patients have more choice and can usually see the specialist they prefer but, if their care is funded by their insurer, the latter may specify where treatment is provided and designate a specific healthcare professional.

Can patients insist on having a particular form of treatment?

No. If patients request treatment that is not clinically indicated, doctors are not obliged to provide it. Rather, the doctor and patient discuss the available treatment options including the risks and benefits of each, taking account of the patient's views and preferences, to reach a decision about what form of treatment would be appropriate. Where a patient refuses all available options, and requests an alternative, the patient's requests should be discussed and the reasons for requesting it explored but, if the doctor still does not believe the treatment request is appropriate, there is no obligation on the doctor to provide it. Disagreements can often be resolved locally by involving an advocate or more senior colleague, for example, but where disagreement continues, it may be appropriate to inform the patient of their right to seek a second opinion.

It is important to be aware, however, that in the case of *Burke v GMC* in 2004, the Court of Appeal held that where a patient with capacity requests clinically-assisted nutrition and hydration (CANH), or does so in advance of losing capacity, this should be provided. The Court was careful to explain that this did not mean that patients had the right to demand particular treatment, but rather that a fundamental aspect of the duty of care is to take all reasonable steps to keep patients alive, where that is their known wish. The question of what is 'reasonable' needs to be considered in the context of each case.

Where a treatment is clinically indicated but is not commissioned, or not available for other reasons, the patient should be informed of this (see section 2.3).

Can patients insist on being prescribed the medication they prefer?

No. Healthcare professionals are responsible for all prescribing decisions they make and for any consequent monitoring that is needed as a result of the prescription given. Furthermore, the decision of whether, or what, to prescribe is a clinical decision based on the presenting symptoms and history. The GMC's guidance *Good practice in prescribing and managing medicines and devices* at paragraph 20 states: 'You are responsible for the prescriptions that you sign. You must only prescribe medicine when you have adequate knowledge of your patient's health and you are satisfied that the medicine serves your patient's needs.'

It can sometimes be difficult to manage patient expectations that they will leave a consultation with a prescription (for example, for antibiotics or the continuation of a prescription that is no longer indicated). Some patients may arrive at a consultation requesting a particular drug they have seen reported in the media, but which may not be appropriate for their condition or circumstances. Such pressure must be resisted; it is not good practice to prescribe medication that is not clinically indicated to avoid confrontation or simply based on patient preference. Whilst a patient's views should be considered, they are only entitled to medication that healthcare professionals believe is appropriate and available within the service. The reasons why such requests cannot be complied with should be explained sensitively to the patient, together with advice about other treatment



options, including self-care and, if the medication requested is clinically indicated but not commissioned, the possibility of obtaining medication outside the NHS (see section 2.3). If after discussion, the patient is not satisfied with the outcome it may be appropriate to inform them of their right to seek a second opinion (see below).

Where a patient requests a named brand rather than a generic medication, doctors should explain that they have an ethical obligation to make the best use of the resources available to provide care for all patients. Unless there are specific, and reasonable, arguments for preferring a particular brand, such requests should be refused.

Do patients have the right to a second opinion?

The GMC's guidance *Good medical practice* at paragraph 18 states that doctors 'must respect the patient's right to seek a second opinion'. This is not the same as saying that NHS patients have a legal *right* to a second NHS opinion. It is generally considered to be good practice, however, to comply with patient requests for second opinions unless there are good reasons to justify a refusal. If a healthcare professional refers a patient for a second NHS opinion, the patient cannot insist on seeing a particular practitioner or provider. A patient who requests a second opinion within the private sector can continue to access other NHS services.

Where a healthcare professional agrees to a patient's request for a second opinion, they should advise the patient that people who are referred for a second opinion are treated as a new patient referral. A second opinion with a different healthcare professional may be at a different clinic or hospital which might involve additional travelling. If they have a serious medical condition requiring urgent treatment, they need to be advised whether any delay in starting treatment due to obtaining a second opinion could have an impact on treatment outcomes.

Refusal or rejection of medical advice

Can competent adults reject medical advice and treatment?

Yes. Competent adult patients are entitled to reject treatment options. Their reasons do not have to be sound or rational; indeed, they do not have to give any reasons at all. Where a competent adult refuses treatment, a healthcare professional is bound to respect that refusal; if they do not, they may face disciplinary action by their regulatory body, plus possible civil action, and criminal proceedings in battery. The only exceptions are when compulsory treatment under mental health legislation is necessary or, in limited circumsances, on public health grounds. However, the healthcare professional's duty of care remains despite the treatment refusal. Paragraph 19 of *Good medical practice* states 'You must not refuse or delay treatment because you feel that patients' actions have contributed to their condition'. This therefore requires a healthcare professional to continue to provide other care and treatments that are within the limits of the patient's consent.

Can competent adult patients refuse hospital admission?

Yes. Adult patients with mental capacity cannot be hospitalised against their will unless they are sectioned under mental health legislation. In such circumstances it is important to explore the reasons for their refusal, to identify whether they are acting under pressure, and to ensure that their decision is not based on a misunderstanding or incorrect information and that they understand the implications of the decision. Sometimes patients will change their mind if they are provided with additional or more accurate information, support, and encouragement, but, if they continue to refuse, that must be respected.



Adult patients with capacity may also discharge themselves from hospital prematurely, but if they do so, or refuse essential treatment, they may be asked to sign a declaration by the hospital confirming that they understand the implications of their decision.

Can adult patients who lack capacity refuse medical treatment?

Capacity is task and time specific and so a patient may be able to refuse consent to some treatments but not others, depending on the seriousness and implications of the decision. An assessment of capacity should be specific to the decision the adult is seeking to take. Undertaking such assessments is a core clinical skill and is the responsibility of the healthcare professional proposing the treatment, although in some complex cases more specialist input may be required. If a patient is not deemed to have the capacity to refuse (or consent to) a particular treatment, the clinician in charge of the patient's care must decide whether that treatment would be in the patient's best interests (or, in Scotland, if the treatment would benefit the patient); any views they express should form part of that assessment.

The Mental Capacity Act 2005 in England and Wales, and the Adults with Incapacity (Scotland) Act 2000 set out the legal framework in respect of all decisions taken on behalf of people who permanently or temporarily lack capacity to make such decisions themselves, including decisions relating to medical treatment. In Northern Ireland, medical decision making is currently governed by the common law with the exception of the provision of care and treatment in circumstances amounting to a deprivation of liberty and research for which there are specific regulations. New legislation combining both mental health and mental capacity law in Northern Ireland has been passed but has not yet been fully implemented. Details of any changes will be posted on the BMA website. The BMA has separate guidance on the treatment of patients who lack capacity and on best interests decision making — see key resources.

Combining NHS and private care

Do patients have the right to combine NHS and private care?

Patients can combine NHS and private care and are increasingly doing so. Patients may, for example, opt for private investigations to obtain a diagnosis before returning to the NHS for any treatment required. On return to the NHS, patients are placed on the waiting list according to their clinical need but will gain an advantage by reaching the waiting list earlier than others with similar clinical needs. Some doctors are uncomfortable with this practice which they see as 'jumping the queue' to the disadvantage of those who are not able to pay for private assessments. Nevertheless, this is an option that is available to patients and doctors who receive requests from patients should answer honestly and in a non-judgemental way. Doctors should be cautious, however, about raising with patients the option of private assessments or treatment in order to be seen more quickly (see below).

The Department of Health has published guidance on NHS patients who wish to pay for additional private care. The guidance states:

- NHS organisations should not withdraw NHS care simply because a patient chooses to buy additional private care.
- Any additional private care must be delivered separately from NHS care.
- The NHS must never charge for NHS care (except where there is specific legislation in place to allow charges) and the NHS should never subsidise private care.



 The NHS should continue to provide free of charge all care that the patient would have been entitled to had they not chosen to have additional private care.'

Difficulties can arise where patients are receiving care simultaneously from two or more providers; this could be where part of the care is provided by the NHS and the rest within the private sector. Communication between those providing care is essential for the wellbeing and safety of patients; this is to prevent different treatments and/or medications being provided inadvertently that interact in a way that could be harmful to the patient or reduce their effectiveness. Encouraging patients to be open about any other sources of treatment they are receiving, and demonstrating a willingness to liaise with other providers, can help to reduce these risks.

What information can be given to patients about private care?

Patients are increasingly choosing to have private investigations or treatment rather than wait for a prolonged period of time to be seen within the NHS. If patients specifically ask for information about alternatives, including private care, healthcare professionals can respond, but particular care is required about raising the issue of private practice with patients.

It is not appropriate for healthcare professionals to use their NHS patient lists to initiate discussion about their private practice or suggest to patients who are on their NHS waiting list that they could treat them more quickly on a private basis. Healthcare professionals should not raise the issue of their private practice obliquely, for example by handing the patient a business card containing the address of both the NHS hospital and the healthcare professional's private consulting rooms, or by adding the private clinic address to NHS letterheads. NHS consultants must manage their private practice as set out in the relevant code of conduct for private practice, and in the terms and conditions of the consultant contract.

Some patients may have private medical insurance which would cover their care and it is not problematic for GPs to ask patients this question when making a referral, so that they can explore that option.

Can patients obtain private prescriptions?

Under the NHS contract, a GP is unable to supply a private prescription to an NHS patient, except under specific circumstances, for example, in connection with foreign travel (for more information see Part 5, Regulation 25 of the National Health Service (General Medical Services contracts)

Regulations 2015). If a patient is advised to be treated with a combination of drugs, some of which are not routinely available as part of NHS commissioned treatment, the patient is entitled to access the NHS funded drugs and can attend a private clinician separately (in a separate episode of care) for those drugs which are not available on the NHS.

Can patients who have tests or investigations in the private sector obtain NHS prescriptions?

Sometimes patients who have investigations in the private sector ask their NHS GP to prescribe any medication recommended. Even if patients opt for private treatment, they are still entitled to NHS services. If the medication is something that GPs would normally be familiar with, the GP considers it to be clinically necessary and they have sufficient information to be able to prescribe safely, they would be required to provide it, even if the assessment from which the need was originally identified was carried out in the private sector. GPs would not, however, be required to prescribe specialist drugs with



which they are not familiar, or those requiring specialist ongoing monitoring. There is also no obligation to prescribe if the medication recommended is not considered by the GP to be clinically necessary, or if it is not funded within the NHS.



Key resources

BMA – Adults with incapacity in Scotland toolkit

BMA – Best interests decision making for adults who lack capacity toolkit (although this is based on the law in England and Wales, the practical information provided may be useful for doctors working in other parts of the UK)

 ${\sf BMA} - \underline{{\sf Mental Capacity Act toolkit}}$

BMA – Mental Capacity in Northern Ireland toolkit

Department of Health – <u>Guidance on NHS patients who wish to pay for additional private care</u>

 ${\sf GMC-\underline{Good\ Medical\ Practice}}$

GMC – Good practice in prescribing and managing medicines and devices



Communication and honesty

Good communication and honesty between healthcare professionals and patients are fundamental to good medical practice. Patients perceive that the communication skills of healthcare professionals are as important as technical skills for determining whether high quality medical care has been provided. Accurate, open, and efficient communication between healthcare professionals is also a key component of providing high quality care to patients.

Communicating with patients

Why is good communication important?

Good communication is about establishing positive interpersonal relationships, as well as exchanging information. A failure to appropriately communicate can not only result in conflict, and a breakdown in trust between the patient and the healthcare professional, it is a significant factor leading to patient harm and complaints. In research carried out by the GMC, the four most common communication failures by doctors that led to patient harm were:

- a failure to provide patients with appropriate and timely information;
- a failure to keep colleagues informed/sharing an appropriate level of information:
- a failure to listen to the patient; and
- a failure to work in partnership or collaboratively with patient/family or carers.

What are the key factors for good communication with patients?

As highlighted by the 2013 campaign 'hello, my name is', very basic aspects of communication can sometimes be forgotten in the hectic and high-pressure environment of healthcare, yet these are crucial to establishing a trusting relationship between patients and those providing care. It is important for patients to know who each member of the team is and, importantly, what their role is. In modern medicine, a number of different professionals collaborate to provide care and treatment and patients need to know whether the person they are speaking to is a doctor, nurse, physiotherapist, or other member of the healthcare team.

All healthcare professionals directly involved in a patient's care should therefore introduce themselves to the patient, and ensure the patient is aware of:

- who is responsible for their clinical care and treatment;
- the roles and responsibilities of the different members of the healthcare team;
- the communication about their care that takes place between members of the healthcare team; and
- what to do and who to contact in different situations, such as 'out of hours' or in an emergency.

The importance of hearing and understanding patient views is a vital part of the doctor-patient relationship. Clear communication is also a key element of the discussion that leads to treatment decisions being made and to ensuring that the patient has given valid consent to any treatments or interventions. Healthcare professionals should try to understand patients' views without making assumptions about the importance they attach to different



outcomes. Healthcare professionals demonstrate effective and respectful communication with patients by:

- exploring the patient's understanding, thoughts, worries and expectations about the problem and taking the patient's input seriously;
- being approachable and friendly, and sharing decision making;
- showing genuine care, and being respectful;
- using plain language, and minimising the use of medical jargon; and
- being specific and checking patient understanding.

What do I need to do if my patient cannot speak English or needs information in a different format?

Good information and communication are essential to high quality, patient-centred care and this means that additional steps are required to assist those who do not speak English or have disabilities which affect their ability to understand the information provided, for example those who need British Sign Language or information provided in Braille. If patients cannot understand the information provided, they cannot give valid consent. High quality, accessible interpretation and translation services should therefore be made available within the NHS, free of charge.

Specific rules apply in Wales where Welsh has official language status. Health Boards in Wales are subject to Welsh language standards in terms of the services they provide to patients. This includes the 'active offer' of services in Welsh. Primary care providers also have certain duties under the Welsh language standards (see key resources) including recording the language preference of patients, making bilingual literature available, and promoting staff training and awareness.

Language preferences or communication needs should be clearly recorded in the medical record and on referral letters, so that suitable arrangements can be put in place including booking an interpreter to be available for appointments where necessary. It should not be left to the patient to find, or bring along, an interpreter – this should be arranged by the healthcare establishment. Family members acting as interpreters should be strongly discouraged because of the risk of technical information not being translated accurately and because of the impact this has on confidentiality. NHS England advises that where clinical staff are bilingual, they should use their professional judgement to decide whether they can competently converse directly with the patient or should use an interpreter.

Information leaflets and other documents that are usually available free of charge to patients should be made available in other languages or formats on request.

Although the NHS provides interpreter facilities, we are aware that these are not always easy to access and are sometimes unable to accommodate requests. If, having contacted these services, a suitable interpreter is not available within the necessary timescale, a judgement will need to be made about whether the consultation should continue, depending on the nature and urgency of the clinical need, and how much the patient has been able to understand. If the consultation continues, the fact that an interpreter had been requested but was not available should be recorded in the medical record. If this is a common occurrence, indicating that the service provided is not meeting the need, this should be drawn to the attention of senior management who have a responsibility to ensure that staff are able to provide information in a way that is understood, in order for the patient's consent to be valid. In general practice, concerns about the ability of the NHS interpreter service to meet demand should be raised with those



commissioning the service. Recording information about unsuccessful attempts to engage an interpreter on the medical record, and raising the issue formally, will help to protect doctors against any future complaints and, by highlighting deficiencies, can prompt improvements to services.

Can I withhold information that I think may be harmful or distressing to the patient?

No. Relevant information, for example about their condition or prognosis, should not be withheld from patients, including at the request of a family member. In the past doctors sometimes tried to protect patients from bad news, or potentially distressing or difficult conversations, by limiting the amount of information provided about the severity of their condition or the options available. This is no longer acceptable. Patients now expect, and have a right, to receive honest and full information, together with the support they need to deal with the information and the anxiety or distress that may flow from it.

The doctor's role is to ensure that decision making is returned, as much as possible, to the patient rather than pre-empting their choices. Even if active treatment is unable to provide a cure, there may still be important goals the patient wants to achieve, or things they want to do or say, if they know they are approaching the end of their life. These discussions, particularly about end-of-life care or decisions about whether to attempt cardiopulmonary resuscitation, are not easy, but they are an essential part of providing medical care. It is important that all doctors have appropriate training in communication skills to equip them to have these conversations.

There may be very exceptional circumstances, when a doctor judges that providing information would cause the patient serious harm. In this context 'serious harm' means more than that the patient will be very upset or may decide to refuse treatment, and the GMC advises that where doctors are considering withholding information, they should seek legal advice.

In the context of patients seeking access to their medical records, it is well-established in law that, in rare cases, certain information should be withheld, including where the relevant healthcare professional considers the information would cause serious harm to the individual or another person; information about this can be found in the BMA's guidance on access to health records (see key resources).

Can patients refuse to receive information?

Information cannot be forced on individuals who do not want to receive it but, for their consent to be valid, patients need to know some basic information about what is proposed; the amount and nature of information required will depend on the individual circumstances (more information can be found in our consent toolkit (see key resources).

Patients with capacity should be encouraged to know information that is important to their health and about the treatment options available. If patients express a wish not to receive that information, the reasons for this should be sensitively explored. Some patients may wish to receive information slowly, over a period of time, and this should be facilitated.

Those who refuse information should be made aware that they can change their mind at any time. Where information is not provided or if only partial information is given — at the patient's request — this should be clearly recorded in the medical record in a form that is easily accessible to others providing care for the patient.



Communicating with colleagues

Should I share patient information with colleagues?

Sharing relevant information, in a timely fashion, with colleagues who are involved in the patient's care is an important part of a doctor's duty of care. Patients who receive good coordination and continuity of care have better health outcomes, higher satisfaction rates, and the healthcare they receive is more cost effective; communication within and between teams involved in the patient's care is an important component of this.

In its guidance *Leadership and management for all doctors* the GMC states at paragraphs 11-13:

- '11. You must make sure that you communicate relevant information clearly to:
 - a. colleagues in your team;
 - b. colleagues in other services with which you work;
 - c. patients and those close to them in a way that they can understand, including who to contact if they have questions or concerns. This is particularly important when patient care is shareOd between teams.
- 12. You should not assume that someone else in the team will pass on information needed for patient care. You should check if you are unclear about the responsibility for communicating information, including during handover, to members of the healthcare team, other services involved in providing care and patients and those close to them.
- 13. You should encourage team members to cooperate and communicate effectively with each other and other teams or colleagues with whom they work. If you identify problems arising from poor communication or unclear responsibilities within or between teams, you should take action to deal with them.'

Healthcare professionals should assess each patient's needs, in terms of communication, coordination, and continuity of care, and consider how those needs will be met. This may involve, if possible, the patient seeing the same healthcare professional throughout a single episode of care or ensuring good communication and continuity within a healthcare team. For patients who use a number of different services, for example, services in both primary and secondary care, or attend different clinics in a hospital, healthcare professionals should ensure effective communication and coordination to permit a smooth transition between services.

In some cases, patients ask doctors not to share information with other healthcare professionals who are providing care; for example, a patient may ask a doctor in secondary care not to provide information to their GP, or vice versa. If the patient is a competent adult, this request should usually be respected even if this leaves the patient (but no one else) at risk of harm (there may be cases where there is an overriding public interest in sharing information, but these cases will be very rare). It is important, however, to discuss with the patient the reasons behind the request (and to provide reassurance about confidentiality if that is the concern) and to ensure the patient has understood the implications of their decision. Where a refusal to share information would impact on the ability to provide safe and effective care, the patient should be informed of this and — where it is the case — they should be told that without certain information, the treatment may not be able to proceed.



Honesty, openness, and truth-telling

Should I tell patients about potentially beneficial treatments that are not available on the NHS?

Yes. Patients should be informed about the range of relevant treatment options, even if there is little or no possibility of a treatment being made available within the NHS. Doctors are often hesitant about mentioning treatment options that they believe their patient cannot afford and are concerned about adding to the patient's distress or encouraging them to get into debt to pay for treatment. It is not, however, appropriate for doctors to make assumptions about their patients' financial situation or to deny patients relevant information because they believe it is not in their interest to know. Without all relevant information, patients cannot make informed decisions.

Doctors should be as open as possible about potentially beneficial treatment options, whilst sensitively explaining why some options may not be available within the NHS. They should be careful not to imply that the patient should pay for private treatment and must not use this discussion to promote any private service they offer.

Do I need to tell the patient if I have made a mistake?

Yes. There is both a legal and ethical duty on doctors (and health and care organisations) to be honest about acknowledging mistakes in diagnosis or treatment. In *Good medical practice* (paragraph 45), the GMC says that if a patient has suffered harm or distress, doctors should:

- `a. put matters right, if possible
- b. apologise (apologising does not, of itself, mean that you are admitting legal liability for what's happened)
- c. explain fully and promptly what has happened and the likely short-term and long-term effects
- d. report the incident in line with your organisation's policy so it can be reviewed or investigated as appropriate and lessons can be learnt and patients protected from harm in the future.'

If the patient lacks capacity to understand, or is a young child, this information should be provided to an appropriate person, which could be a family member or carer of an adult, or the parent of a child. The Health and Social Care (Quality and Engagement) (Wales) Act 2020 strengthens the existing duties on NHS bodies in Wales, introducing (from April 2023) an organisational duty of candour on providers of NHS services (see key resources).

Whilst it is important to take action promptly when a mistake has been made, thought should be given to the best way to approach this (seeking advice from defence bodies or legal advisors, where appropriate). Such discussions need to be sensitively and carefully handled, acknowledging the error and the likely impact of this on the patient. In some cases, patients will need extra support, or counselling, to help them come to terms with the situation.

If a clinician believes that a previous doctor has made a mistake, missed important signs of a serious condition or that tests results may have been misinterpreted, they have an obligation to take action to ensure the patient is informed and that appropriate steps are taken, where possible, to put matters right. It is important that lessons are learnt from mistakes and, where there is a pattern of error, that it is reported to prevent other patients from being harmed. Joint GMC and Nursing and Midwifery Council (NMC) guidance also highlights the duty on healthcare professionals to be open and honest with their organisations by reporting incidents and near-misses to encourage a learning culture.



Can I withhold or remove relevant information from third party reports at a patient's request?

No. Patients often ask doctors to write reports for non-medical matters such as in connection with employment, benefits, or to support applications for firearms licences (the BMA has separate guidance on the firearms licensing process – see key resources). There is no obligation on doctors to comply with such requests but if they agree to do so they must do so honestly and must only sign reports that they believe to be true. We occasionally receive enquiries from doctors who have been asked by their patient to withhold relevant information from a report – in order to make the report more favourable to them, for example. As with all other areas of their professional lives, doctors must be honest and trustworthy and should not therefore accede to such requests. The GMC, in *Good medical practice*, states:

- '88. You must be honest and trustworthy, and maintain patient confidentiality in all your professional written, verbal and digital communications.
- 89. You must make sure any information you communicate as a medical professional is accurate, not false or misleading. This means:
 - a. you must take reasonable steps to check the information is accurate
 - b. you must not deliberately leave out relevant information
 - c. you must not minimise or trivialise risks of harm
 - d. you must not present opinion as established fact.'

The BMA advises that reports may be written with information omitted but in such cases it must be clearly marked to state that some information has been withheld at the request of the patient.



Key resources

BMA – Consent and refusal by adults with decision-making capacity.

A toolkit for doctors

BMA – Guidance on access to health records

BMA - The NHS Wales Duty of Candour

BMA – The firearms licensing process

GMC – <u>Decision making and consent</u>

GMC – <u>Disclosing information for employment</u>, insurance and similar purposes

GMC - Good Medical Practice

GMC – <u>Leadership and management for all doctors</u>

GMC – <u>Understanding communication failures involving doctors (2019)</u>

GMC and NMC – Openness and honesty when things go wrong. The professional duty of candour

NHS England – <u>Guidance for commissioners. Interpreting and translation</u> <u>services in primary care (2018)</u>

Public Health Scotland – <u>Interpreting, communication support and translation</u>. National policy (2020)



Maintaining professional boundaries

The doctor-patient relationship is built on trust and doctors have particular ethical and professional obligations to ensure that appropriate professional boundaries are maintained. Although this is often considered only in terms of sexual or close emotional relationships, there are other common scenarios where questions of professional boundaries arise. There will be occasions where doctors meet patients socially and a friendship develops or where they work together in external ventures, such as local charities, but care should always be taken to ensure that professional boundaries remain.

Personal relationships

British Medical Association

Why is maintaining professional boundaries so important?

Although the nature of the relationship between doctors and their patients has changed over recent years, with greater emphasis on partnership and patient autonomy, it is still the case that the relationship is not an equal one. There is an inevitable power imbalance, doctors have access to sensitive personal health data about patients and some patients who are seeking medical care may be in a very vulnerable position. Whilst a friendship or relationship may not influence a doctor's actions or decisions in any way, there may be a perception that it has or might have done. Doctors can also be vulnerable to complaints if a personal, or other non-clinical, relationship (for example a business arrangement) with a patient breaks down.

What type of relationship might be considered 'improper'?

GMC guidance (Maintaining a professional boundary between you and your patient) states:

'Current patients

- 9. You must not pursue a sexual or improper emotional relationship with a current patient.
- 10. If a patient pursues a sexual or improper relationship with you, you should try to reestablish a professional boundary, if it is safe to do so. If trust has broken down and you find it necessary to end the professional relationship, you must follow the guidance in *Ending your professional relationship with a patient*.
- 11. You must not use your professional relationship with a patient to pursue a personal relationship with someone close to them. For example, you must not use home visits to pursue a relationship with a member of a patient's family.

Former patients

- 12. Personal relationships with former patients may also be inappropriate depending on factors such as:
 - a. the length of time since the professional relationship ended (see paragraphs 13–14)
 - b. the nature of the previous professional relationship
 - c. whether the patient was particularly vulnerable at the time of the professional relationship, and whether they are still vulnerable (see paragraphs 15–18)
 - d. whether you will be caring for other members of the patient's family



- e. whether the patient's decisions and actions are influenced by the previous relationship between you (or could be seen to be)
- f. whether you would be (or could be seen to be) abusing your professional position.'

Any sexual relationship with a patient is very likely to be deemed 'improper' even if it is a consensual relationship that developed in a social setting. The GMC's guidance is clear that you must not pursue a sexual relationship and must politely reject any sexual advances from patients. This strict prohibition extends to relationships with someone close to a patient and, in some circumstances, to former patients (depending on the time that has elapsed and the nature of the professional relationship).

There are some situations that doctors face where, in seeking to provide support to patients and their families, they could inadvertently step beyond the professional boundary. There is a risk of emotional attachment developing, for example, when patients seek support at times of emotional difficulty, after a loss or bereavement for example, or where a patient's relatives are vulnerable during a patient's acute or terminal illness. These types of scenarios require particularly sensitive handling to avoid a situation of emotional dependence arising or of the relationship extending beyond that expected of a professional doctor-patient relationship. A similar type of dependence can also arise where a doctor offers to help a patient with non-medical matters (such as completing benefits claims) when they are struggling but which, over time, leads to an expectation of ongoing support, making it difficult to refuse and extending their role beyond the usual professional role of the doctor. An awareness of how these issues can develop, if not carefully managed, can help doctors take steps to avoid this situation arising.

Other types of relationships with patients may also be considered improper although much will depend on the individual circumstances. Doctors should be alert to this and consider whether friendships, or other types of non-clinical relationships, with patients could be perceived as in any way inappropriate.

What should I do if I start a relationship with someone I meet socially and then realise they are a patient?

Personal relationships can arise in good faith when doctors and patients meet in a purely social setting, but it is essential that doctors take steps to establish and maintain professional boundaries. If they subsequently discover that the person with whom they are developing a relationship is on their patient list, they should take immediate steps to cease either the personal or professional relationship. If they have never seen the patient, they should prevent any professional relationship developing, for example by ensuring that, when seeking treatment, the patient is allocated to another doctor. This may be awkward, and appear presumptuous, particularly at the beginning of a relationship but is always advisable.



Can I accept 'friend' or 'follow' requests from patients on social media?

Like other people, many doctors are prolific on social media and use this as a source of information and for campaigning on issues they believe in, including to promote health messages to their patients. Care is needed, however, to ensure this does not blur the boundaries between doctors' private and professional lives in a way that leads to ethical challenges. The GMC expects the same standards to be adhered to when communicating with patients on social media as they would face-to-face or on the telephone. Material posted onto social media sites, intended for friends, can be accessible to others, including patients. This means that patients may gain personal information about their doctor and their social life that could have an impact on the doctor-patient relationship and breach professional boundaries.

Doctors are advised, where possible, to try to maintain a professional distance from patients on social media, using appropriate privacy settings to limit access to personal material. If social media sites are used as a personal space, it is inadvisable to accept 'friend' or 'follow' requests from patients. Where GPs are part of local social media groups, it is likely that some other members will be registered with their practice; doctors should therefore be mindful that information they post may be accessible to patients.

Can I enter a business arrangement or transaction with a patient?

There is nothing to prevent doctors from entering into a business arrangement with a patient, where that is completely separate from their clinical relationship, but such arrangements should be approached with caution. For example, thought should be given to how this might be viewed by the patient and others, whether it could be perceived as a conflict of interests and whether it could have any impact on the clinical relationship, including if the business relationship were to break down or become acrimonious. It may be advisable before entering into any such arrangement to discuss the situation with the individual and suggest that it might be best for them to transfer to another doctor. It would never be appropriate for a doctor to approach a patient about investing in their business enterprise or to seek help or support for their own endeavours. Any such approach could put patients under pressure to accept and be seen as the doctor inappropriately using their position to gain personal advantage. This extends to non-financial interests. For example, we have been asked in the past whether it is appropriate for doctors to ask patients to put up posters to support their candidacy in local elections, or to ask patients to sponsor them for a charitable event. In our view, making such requests would risk crossing the professional boundaries of the doctor-patient relationship.



Treating colleagues, friends, and family

Can I employ someone who is a patient?

Staff who work in a GP practice should be encouraged to register as a patient elsewhere to ensure a clear professional boundary, but it would not be appropriate to refuse someone employment on the basis that they are currently a patient. There should be a discussion about some of the challenges of having an employee-employer relationship alongside a clinical one. This includes issues around confidentiality, the management of situations where a patient needs to take a lot of sick leave, and the challenge that could arise if disciplinary proceedings needed to be invoked. Current employees who are also patients should be encouraged to register with another practice but in some small communities this may not be possible, or the patient may wish to remain with their current practice, and they cannot be required to move. Where staff members are also patients, it is essential that medical records are only used for the provision of care and not for any employment matters, unless explicit consent is provided by the patient.

Specific information about providing care for medical colleagues can be found in section 2.8.

Can I treat family members and friends?

It is not good practice for doctors to treat their family members and friends and every year a number of doctors are reported to the GMC for doing so — some having been reported by pharmacists or other medical colleagues. Many of these cases are resolved quickly, where there is evidence that it was a one-off incident where there was no other option available for example, but in other cases doctors are the subject of lengthy investigations and end up having sanctions imposed.

The GMC's guidance at paragraph 97 of *Good medical practice* is clear that doctors must, 'wherever possible, avoid providing medical care to yourself or anyone with whom you have a close personal relationship.' The BMA therefore advises against prescribing for close friends and family members except in rare circumstances where there is no other reasonable option available; in an emergency, for example, or providing a one-off prescription for antibiotics for a chest infection where there is nobody else available to prescribe. If you decide to do so, the GMC's guidance on prescribing (see key resources) requires (at paragraphs 68-69) that 'you must make a clear record at the same time or as soon as possible afterwards; the record should include your relationship to the patient, where relevant, and the reason it was necessary for you to prescribe.' Controlled drugs should only ever be provided outside an established clinical relationship where it is necessary to avoid serious harm and no other option is available.

GPs should encourage family members and friends to register with a different practice and doctors in secondary care should declare the relationship and make arrangements for care to be undertaken by a different doctor. This separation of the professional and personal relationship is an important part of maintaining professional boundaries. It also protects confidentiality and ensures objectivity, avoiding the risk of emotion or pressure impacting (or being perceived to have an impact) on the doctor's clinical judgement.



Even if they are formally being seen by another doctor, family members or friends sometimes ask for 'informal' medical advice. It can seem difficult to refuse to help when requested in this way, but it is important that those requiring medical care are seen in a formal setting; informal 'consultations' can lead to significant health issues being missed or false reassurance being given. In addition, as only those with a legitimate, established clinical relationship can access an individual's medical record, doctors treating family or friends informally may be unaware of relevant information that could affect their prescribing decision. In an emergency situation, if it is necessary to consult the individual's medical record in order to provide safe and effective treatment to a friend or family member, this should be recorded on the medical record with a note about when and why the record was accessed.

Doctors also need to be careful about requests from family and friends to comment on their doctors' decisions or advice; without all of the information and test results, such comments would be made on partial evidence and could undermine the patient's trust in their doctor and the care they are receiving.

Gifts and bequests

Can I give a small gift to my patient?

Doctors sometimes ask if it would be acceptable to send flowers, or buy concert tickets, to cheer up a patient who is having a difficult time. Whilst the motivation for this is laudable, it is important to consider how this could be interpreted by the patient, or by others, and whether this is consistent with the professional nature of the relationship; for these reasons we generally advise against the giving of even very small gifts to patients.

Can I accept gifts from patients?

Occasionally, doctors are offered gifts by patients or their families who wish to thank them for the care they have provided. NHS staff in England can accept gifts up to the value of £50 (and these do not need to be declared). Any gifts to NHS staff in England with a value of more than £50 – including the cumulative worth of gifts over a 12-month period – must be refused by individuals (although they may be accepted into an organisation's charitable fund). Any offers of cash, or vouchers, irrespective of the value, must also be declined. Individual Trusts are likely to have their own policies and procedures for declaring gifts in accordance with the national guidance.

Although there is no national guidance on accepting gifts in Scotland, Wales and Northern Ireland, similar rules will apply; these are likely to be set out in guidance within individual establishments and so doctors should ensure they are familiar with the rules that apply where they work.

Any doctor who is offered a gift from a patient is responsible for ensuring that this is within the rules set out by their Trust or Health Board.

Most general practitioners are not NHS employees and are therefore permitted to accept gifts from patients but are required to keep a register of all gifts accepted that are worth more than £100. This applies to all GPs, including locums, across the UK.



When accepting any gifts from patients or their families, doctors must make clear that this will not in any way influence the care or treatment the patient will received. The GMC makes clear in *Good medical practice*, at paragraph 96, that:

'You must not ask for or accept – from patients, colleagues or others – any incentive, payments, gifts or hospitality that may affect or be seen to affect the way you propose, provide or prescribe treatments, refer or commission services for patients. You must not offer such incentives to others.'

I have been left some money in a patient's will, can I accept it?

Sometimes, doctors are informed after a patient's death that money or possessions have been left to them in a patient's will. The rules set out above apply irrespective of whether the patient was alive or dead at the time the doctor became aware of the gift. If it is not possible for a doctor to accept a bequest, it may be possible for the money or items to be donated through the NHS establishment's charitable fund or to a registered charity of the doctor's choice. Advice should be taken on the individual circumstances.



Key resources

BMA - Receiving gifts from patients (GPs)

BMA – <u>Social media</u>, ethics and professionalism

GMC – Good practice in prescribing and managing medicines and devices

GMC – <u>Identifying and tackling sexual misconduct – ethical topic</u>

GMC – Maintaining personal and professional boundaries

GMC – Using social media as a medical professional

NHS England – Managing conflicts of interests in the NHS

Trust and mutual respect

Trust in both parties is essential to the doctor-patient relationship. This involves a mutual commitment to honesty, openness, and transparency. Trust is linked to good communication, the maintenance of strong professional boundaries, and respect for confidential information. It also involves mutual respect and a joint search for positive outcomes. This section looks at circumstances where trust may be perceived to be under pressure from one or other party to the relationship.

Video and audio recordings

What if a patient asks to record a consultation?

Patients sometimes ask to record consultations. Given the availability of smart phones and other recording devices, such requests are likely to become more frequent. Although such requests have been perceived as signalling a lack of trust, or an intention to pursue a complaint, many patients request recording as a form of note taking; particularly if the information is complex, they have cognitive difficulties, or they are distressed or otherwise unable to retain information easily.

In our view, doctors should ordinarily encourage patients to make open and contemporaneous recordings to assist them in decision making and self-care. Such recordings should, however, be made openly. As with patients, doctors have privacy rights. Covert recording of consultations, as well as any subsequent publication of the recording, or parts of it, in publicly-accessible media, without explicit agreement, is a breach of doctors' privacy rights and may open patients up to legal proceedings. Doctors should consider posting information about their policy on making recordings in their practice or health facility. The BMA has separate guidance about how to manage situations where patients post consultations online (see key resources).

Can I record patients covertly if I have welfare concerns?

The use of covert recording is sometimes suggested where, for example, there are concerns about the wellbeing of a child and grounds for suspecting that parents or carers are causing the child harm. The use of covert recording should only be considered where there are no other feasible means to obtain information essential to the investigation or prosecution of a serious crime, or to protect someone from serious harm.

In the UK, any covert recording by the NHS, or those employed by or contracted to the NHS, come under the *Regulation of Investigatory Powers Act 2000* or the *Regulation of Investigatory Powers (Scotland) Act 2000*. If you are considering using covert recordings you must therefore ensure that you comply with the relevant legislation. In addition, as paragraph 54 of the GMC's guidance on audio and video recordings states:

'If you consider making covert recordings, you must discuss this with colleagues, your employing or contracting body, and relevant agencies, except where this would undermine the purpose of the recording, in which case you should seek independent advice. You must follow national or local guidance.'



Covert medication

Can I covertly medicate my patients?

Where a patient retains relevant decision-making capacity, covert medication is unacceptable. It would involve the deliberate deception of a competent patient and clearly breaches the ethical and legal requirement to seek informed consent from capacitous patients for any treatment. Where there are doubts as to a patient's capacity, a formal assessment should be undertaken. Patients must not be misled as to the purposes of any treatment or medication.

Cases may arise however where covert medication might be in the best interests of a patient who lacks the capacity to consent to it. Any such decision must be taken by the clinician in overall charge of the care of the patient lacking capacity, in consultation with the multi-disciplinary care team. Those close to the patient, including anyone with formal decision-making powers, must be involved in the decision. The reasons for administering the drugs covertly should be recorded in the patient's care plan and regularly reviewed. Consideration must always be given to whether there are options available that are more respectful of the individual's free choice. It is advisable to seek legal advice where covert medication is proposed for a patient on a regular or long-term basis.

Conflicts of interests

What should I do if I think I might have a conflict of interest?

Doctors are under an obligation to make decisions based upon their assessment of what is best for their patients. Personal factors, such as any possible financial or other advantage for the doctor, or those close to the doctor, must not factor in the decision making. Both the BMA and the GMC stress the importance of doctors identifying possible conflicts of interests. Where they cannot reasonably be avoided, doctors should be open and honest about such conflicts of interest. Similarly, doctors must be open and honest about their financial arrangements. Doctors must not accept any inducement, gift, or hospitality that may affect — or be seen to affect — the way they treat, prescribe or refer patients, or commission services for their patients.

The BMA has specific guidance on transparency and doctors with competing interests (see key resources).

Chaperones

When is it necessary to use a chaperone?

Doctors and patients can sometimes be reluctant to ask for a chaperone, for fear that it indicates a lack of trust in the other party. Both the BMA and the GMC, however, recommend that patients are offered a chaperone for intimate examinations wherever possible, irrespective of their gender.

The presence of a chaperone helps to protect and support patients and doctors. Incidences of inappropriate behaviour by doctors are very rare but, given the nature of intimate examinations, concerns and complaints can sometimes arise as a result of misunderstanding or poor communication. The fact of offering a chaperone highlights the sensitive nature of the clinical encounter, which should raise awareness that particular care is needed to ensure proper explanation, communication, respect, and dignity, and that valid consent has been provided for the examination to proceed. This can help to prevent complaints occurring. Where a chaperone is present, they are able to provide an independent account of events should any complaint be made. A note should be made in the medical record of the name of any chaperone provided.



GMC guidance (see key resources) states that when an intimate examination is being carried out a chaperone should be offered wherever possible, and this person should usually be a healthcare professional.

What individuals consider to be 'intimate' varies and should be considered from the patients' perspective. It is likely to include examinations of the breasts, genitalia, and rectum, but may include any situation where patients might feel uncomfortable about being alone with a doctor, such as when it is necessary to darken the room for a retinopathy or remove an item of clothing.

Doctors sometimes find themselves in situations where it is simply not possible to offer a chaperone. In these circumstances, a judgement will need to be made about whether the consultation should continue, depending on the urgency of the clinical need and the views of the patient about whether to proceed or reschedule the appointment. If the consultation continues, the fact that no suitable chaperone was available – and that the patient consented to continuing without a chaperone—should be recorded in the medical record. If this is a common occurrence, for example due to staffing levels within the establishment, this should be drawn to the attention of senior management who have a responsibility to ensure that staff are able to comply with the requirements of the regulator. In general practice, where this could be particularly difficult, careful planning will be required to ensure that this part of GMC guidance can be met. One option, where it is known that an intimate examination will, or is likely to, be required, would be for patients to be provided with information and asked to give advance notification, for example in an appointment letter, if they would like a chaperone provided, so that suitable arrangements can be made.

A relative or friend of the patient is not an impartial observer and so would not be a suitable chaperone, but doctors should be sympathetic to a reasonable request to have such a person present as well as a chaperone, or when no chaperone is available.

Occasionally there may be disagreements over the use of a chaperone. Where a doctor feels uncomfortable about going ahead without a chaperone, but the patient refuses, paragraph 22 of the GMC's guidance on intimate examinations and chaperones states:

'you must explain clearly why you want a chaperone present. If the patient wishes to proceed without a chaperone but you remain uncomfortable with this, you may wish to consider referring the patient to a colleague who would be willing to examine them without a chaperone, as long as the delay would not adversely affect the patient's health. If you feel your personal safety is at risk you should follow the guidance in *Maintaining personal and professional boundaries or Ending a professional relationship with a patient.*'

Where the consultation is postponed, or care is passed on to another doctor, the reasons for this should be stated in full in the medical record. This should include the assessment undertaken of the risk to the patient of any subsequent delay. All discussions with patients about chaperones should be carefully recorded in the patient's medical record, including, if the patient does not want a chaperone, the fact that the offer was made but the patient declined.

Urgently needed medical care should not be delayed because there is no chaperone available. The circumstances necessitating the decision to proceed should be recorded in the medical record.





Key resources

BMA – <u>Patients recording consultations</u>

BMA – <u>Transparency and doctors with competing interests</u>

 ${\sf CQC-} \underbrace{{\sf Covert\ administration\ of\ medicines}}$

GMC – Good Medical Practice

GMC – Making and using visual and audio recordings of patients

 ${\sf GMC-} \underline{\sf Making\ recordings\ covertly-ethical\ guidance}$

GMC – <u>Intimate examinations and chaperones</u>



Conscientious objection and expressing personal beliefs

What is a conscientious objection?

Doctors are entitled to have their own personal beliefs and values in the same way as any other member of society. A conscientious objection is when a doctor does not wish to provide, or participate in, a legal and clinically appropriate treatment or procedure because it conflicts with their personal beliefs or values. A conscientious objection is based on sincerely held beliefs and moral concerns, not self-interest or discrimination. Doctors can therefore only claim a conscientious objection provided it is lawful, non-discriminatory, and does not cause patients harm or deny them access to appropriate medical treatment or services.

The BMA does not want to unnecessarily restrict doctors from seeking to exercise a conscientious objection or other expressions of their belief. We seek to balance doctors' freedom with the rights of patients to receive appropriate treatment in a non-judgemental fashion.

Rights and limits to conscientious objection

Is there a legal right to conscientious objection?

There are only two areas in the UK where there is a statutory right to claim a conscientious objection; these are abortion and fertility treatment.

- Abortion Section 4(1) of the Abortion Act 1967 (Scotland, England, and Wales) and section 12 of the Abortion (Northern Ireland) (No. 2)
 Regulations 2020 provide that a healthcare professional cannot be compelled to participate in the administration of a procedure which results in the termination of a pregnancy if they have a conscientious objection, except where it is necessary to save the life, prevent grave permanent injury to the physical, or mental health of a pregnant woman. There is no statutory right to conscientious objection in the case of emergency hormonal contraception as this is not an abortifacient.
- Fertility treatment Section 38 of the Human Fertilisation and Embryology Act 1990 provides that a healthcare professional cannot be compelled to participate in any activity covered in that legislation (assisted reproduction and embryo research) if they have a conscientious objection.

Are there any limits to the statutory rights of conscientious objection?

The limits of conscientious objection in abortion were confirmed in the UK case of Janaway v Salford Area Health Authority (1988) which held that the right is limited to a refusal to participate in the procedure(s) itself and not to pre- or post-treatment care, advice, or management. The position was further clarified in the case of Greater Glasgow v Doogan and Another (2014) in which the Supreme Court held that conscientious objection does not extend to healthcare professionals supporting, supervising, and delegating to staff participating in abortion. Furthermore, in an emergency, healthcare professionals must provide appropriate care and treatment despite any conscientious objection.



Should doctors be able to exercise a right of conscientious objection outside the limited statutory rights of abortion and fertility treatment?

Yes. Subject to the provisos below, the BMA believes doctors should have a right to conscientiously object to participation in other legal and clinically appropriate treatments. For example, contraception, non-therapeutic male infant circumcision (NTMC), and the withdrawal of life-sustaining treatment.

However, this right does not extend to refusing to treat a patient where this would give rise to direct or indirect discrimination, or harassment, under the Equality Act 2010 in England Wales and Scotland or parallel legislation in Northern Ireland, in other words, on the grounds of patient's age, disability, marital status, pregnancy, race, religion or belief, sex, and sexual orientation. This means for example, that a doctor must not refuse to provide a patient with clinically appropriate medical services because the patient is proposing to undergo, is undergoing, or has undergone gender reassignment, or a refusal to treat patients of the opposite sex. It is the procedure itself that the conscientious objection refers to, not specific characteristics of the patient.

It should also be noted that doctors may be required to fulfil contractual requirements that may restrict their freedom to work in accordance with their personal beliefs. For example, where the treatment is a core service, such as contraception, and all the GPs in a practice have a conscientious objection to its provision, they must make alternative arrangements for their patients by subcontracting this part of the service.

Responsibilities of those with a conscientious objections

What are the responsibilities of doctors who have a conscientious objection to a treatment or procedure that may be clinically appropriate for the patient?

Where a doctor will not provide or participate in a treatment or procedure based on a conscientious objection this can affect patient care. The BMA believes that they have an ethical obligation to minimise disruption to patient care and must not use a conscientious objection to intentionally impede patient access to care. Furthermore, in an emergency, doctors must provide appropriate care and treatment despite any conscientious objection.

The GMC advises that where a doctor has a conscientious objection to a legal and clinically appropriate procedure or treatment, patients should be made aware of this in advance of a consultation. In its guidance *Personal beliefs and medical practice*, the GMC states at paragraph 10 'If, having taken account of your legal and ethical obligations, you wish to exercise a conscientious objection to services or procedures, you must do your best to make sure that patients who may consult you about it are aware of your objection in advance. You can do this by making sure that any printed material about your practice and the services you provide explains if there are any services you will not normally provide because of a conscientious objection.'

In addition, the GMC in its guidance *Personal beliefs and medical* practice at paragraph 12 states 'Patients have a right to information about their condition and the options open to them. If you have a conscientious objection to a treatment or procedure that may be clinically appropriate for the patient, you must do the following.

a. Tell the patient that you do not provide the treatment or procedure, being careful not to cause distress. You may wish to mention the reason for your objection, but you must be careful not to imply any judgement of the patient.



- b. Tell the patient that they have a right to discuss their condition and the options for treatment (including the option that you object to) with another practitioner who does not hold the same objection as you and can advise them about the treatment or procedure you object to.
- c. Make sure that the patient has enough information to arrange to see another doctor who does not hold the same objection as you.'

If a patient wishes to be seen by another healthcare professional, the doctor must ensure they have sufficient information to enable them to do so. If it is not practical for the patient to make the arrangements themselves, the doctor must arrange for another healthcare professional to take over their care without delay. It is important to ensure that any inconvenience or distress to the patient is kept to a minimum.

Doctors should also inform their employer and colleagues about their conscientious objection so that they can practise in accordance with their beliefs without compromising patient care or over-burdening colleagues.

Can doctors exercise a right of conscientious objection to patient 'life-style' choices?

No. It is not appropriate for doctors to refuse to treat patients whose illnesses are thought to arise from their personal choices, for example, smoking, alcohol, and drugs. The GMC in its guidance *Good medical practice* states at paragraph 19 'You must treat patients fairly. You must not discriminate against them or allow your personal views to affect your relationship with them, or the treatment you provide or arrange. You must not refuse or delay treatment because you believe that a patient's actions or choices contributed to their condition.' Patients should be offered information about how to safeguard their health but the fact that their actions may have contributed to their condition should not give rise to moralising or delaying treatment.

Expressing personal beliefs

Can doctors express or discuss their personal beliefs with patients?

The GMC in its guidance *Personal beliefs and medical practice* states at paragraph 31 'You may talk about your own personal beliefs only if a patient asks you directly about them or indicates they would welcome such a discussion. You must not impose your beliefs and values on patients, or cause distress by the inappropriate or insensitive expression of them.' In the case of <u>Kuteh v Dartford and Gravesham NHS Trust (2019)</u> the Court of Appeal upheld the dismissal of a nurse after she initiated conversations with patients about religion, assured her employer that she would stop, yet continued to do so, told patients they had a better chance of survival if they prayed, gave patients bibles, and asked a patient to sing a psalm with her.

Some doctors may seek to manifest religious or cultural beliefs or views through the wearing of religious symbols. Like the GMC, the BMA does not seek to tell doctors what to wear. However, the BMA anticipates that doctors will be sensitive to the impact that such symbols may have on their patients.



Does the BMA have any further guidance on conscientious objection?

Yes, the BMA has information on conscientious objection in its guidance on abortion, non-therapeutic male circumcision (NTMC), the licensing of firearms, and clinically-assisted nutrition and hydration (CANH) — see key resources below.



Key resources

BMA – Clinically-assisted nutrition and hydration

BMA – Non-therapeutic male circumcision (NTMC) of children – practical guidance for doctors

BMA – The firearms licensing process

BMA – The law and ethics of abortion

GMC - Good Medical Practice

GMC – Personal beliefs and medical practice

Human Fertilisation and Embryology Authority – Code of Practice 9th Edition



Care at a distance

The COVID-19 pandemic accelerated the mainstream adoption of remote consultations, monitoring, treatment, and prescribing, either by phone, video, online, or via apps. As technology advances and new, innovative models of care provision are introduced, providing care at a distance is likely to expand and develop further. When used appropriately, there are a range of benefits for patients, doctors, and service providers of remote access to treatment when compared with traditional face-to-face care. However, there can be additional risks to practising remotely and there will always be circumstances in which traditional, in-person care is either preferable or necessary. As with face-to-face consultation, a doctor's primary obligation is to make the care of their patients their first concern. If they have a reasonable belief that this cannot be done safely and effectively by remote means, they should make all reasonable efforts to see the patient in person.

High-level principles

What obligations do I have when providing care remotely?

All relevant legal, ethical, and regulatory obligations apply equally to care provided virtually or remotely as they do to in-person care. This includes consent, confidentiality, data management, capacity, and prescribing. There may also be specific clinical guidelines that doctors should follow which relate to remote care in their area of practice.

UK healthcare regulators and medical bodies have outlined ten high-level principles that registered healthcare professionals, including doctors, should follow in remote consultations and prescribing.

They should:

- 1. 'Make patient safety the first priority and raise concerns if the service or system they are working in does not have adequate patient safeguards including appropriate identity and verification checks.
- 2. Understand how to identify vulnerable patients and take appropriate steps to protect them.
- 3. Tell patients their name, role and (if online) professional registration details, establish a dialogue and make sure the patient understands how the remote consultation is going to work.
- 4. Explain that:
 - a. They can only prescribe if it is safe to do so.
 - b. It's not safe if they don't have sufficient information about the patient's health or if remote care is unsuitable to meet their needs.
 - c. It may be unsafe if relevant information is not shared with other healthcare providers involved in their care.
 - d. If they can't prescribe because it's unsafe, they will sign post to other services.
- 5. Obtain informed consent and follow relevant mental capacity law and codes of practice.
- Undertake an adequate clinical assessment and access medical records or verify important information by examination or testing where necessary.
- 7. Give patients information about all the options available to them, including declining treatment, in a way they can understand.
- Make appropriate arrangements for after care and, unless the patient objects, share all relevant information with colleagues and other health and social care providers involved in their care to support ongoing monitoring and treatment.



- 9. Keep notes that fully explain and justify the decisions they make.
- 10. Stay up to date with relevant training, support and guidance for providing healthcare in a remote context.'

Deciding between remote and face-to-face consultations

When is a remote consultation appropriate?

Different medical specialties use remote consultations in different ways and circumstances relevant to that specific area of practice. In general, they are most obviously suitable for straightforward requests for treatment from patients with capacity, where a physical examination is not necessary, and when there is access to the patient's notes. However, in all circumstances it will still be important to exercise judgement in determining whether it is appropriate for an individual patient. Relevant factors might include any safeguarding concerns, whether they can access the consultation privately, and how comfortable they are in using the technology. Doctors must also ensure that they are able to conduct the consultation safely and confidentially. The General Medical Council has a flowchart to help doctors decide when it may be safe and appropriate to treat patients remotely.

Can patients insist on a face-to-face consultation?

In paragraph 21 of its guidance on prescribing (see key resources), the GMC advises that, where there is the option of either a face-to-face or remote consultation, 'when it is within your power, you should agree with the patient which mode of consultation is most suitable for them.' While doctors have a responsibility to take account of the resources available to them, if a patient has reservations about a remote consultation or does not feel that it appropriately suits their needs, then this must be taken into consideration.

When might remote consultations and prescribing not be appropriate or additional caution might be required?

In paragraph 22 of its guidance on prescribing (see key resources), the GMC advises that a face-to-face consultation may be more appropriate when a doctor:

- is unsure about a patient's capacity to consent to treatment;
- needs to physically examine the patient;
- is not the patient's usual doctor or GP and the patient has not given their consent for the sharing of information from the consultation with their regular prescriber;
- is concerned that the patient is not able to access the consultation safely and confidentially; or
- is concerned the patient may be unable to make a free and voluntary decision, for example if they are under pressure from others.

Prescribing remotely

Can I prescribe remotely?

Yes. As with any prescription, healthcare professionals take full legal and ethical responsibility for the decision and should only prescribe when they have sufficient knowledge and experience to be satisfied that it is appropriate for the patient's needs. Doctors should follow the GMC's guidance on *Good practice in prescribing and managing medicines and devices* at all times.

When prescribing controlled drugs remotely, the GMC advises that doctors must ensure that additional safeguards are in place, including robust patient



identity checks, confirmation that the patient has given consent for their regular prescriber to be contacted about the prescription, and that all relevant information is shared with the patient's GP or primary care provider. Patients must also be given the 'names, roles, and contact details of key people who will be involved in their care, as well as advice about who they can contact if they have any questions or concerns.' Injectable cosmetic products must not be prescribed via a remote consultation.

Can I prescribe to patients who are overseas?

Yes, although depending on the circumstances, doctors should approach such requests with caution and carefully assess the risks involved. The GMC outlines additional factors that doctors will need to consider, in addition to the principles outlined above. This includes how the patient will be monitored, differences in a product's licensed name, indications and dosage, and the indemnity and registration requirements that may be necessary to both practise and prescribe in the countries involved. Doctors are also expected to follow UK and overseas legal requirements as well as relevant guidance on import and export for safe delivery, including from the MHRA.



Key resources

GMC – Ethical hub: remote consultations

GMC – Good practice in prescribing and managing medicines and devices

GMC – Remote prescribing: high-level principles



Doctors' responsibilities

British Medical Association

A doctor's fundamental professional duty to make the care of their patients their first concern intersects with responsibilities to ensure their own health and conduct, or that of their colleagues, does not risk patient safety or call into question their fitness to practise. This section addresses issues including doctors diagnosing or treating themselves, and their responsibilities where they have concerns about their colleague's health or performance.

Doctors' health and healthcare

What responsibilities do I have to ensure that my own health does not affect patient care or safety?

Doctors are routinely exposed to health risks in the course of their work, including exposure to infection and needle-stick injuries (see key resources). Doctors have a responsibility to ensure that their health does not adversely affect the care of their patients. In paragraph 79 of *Good medical practice*, the GMC states that

You must consult a suitably qualified professional and follow their advice about any changes to your practice they consider necessary if:

- a. you know or suspect that you have a serious condition that you could pass on to patients
- b. your judgement or performance could be affected by a condition or its treatment.

You must not rely on your own assessment of the risk to patients.'

It further states that doctors should be immunised against common serious communicable diseases unless contraindicated.

In addition to the risks of infection, long hours, workload pressures, dealing with organisational change, and coping with patients' anxieties can also take a toll on doctors' physical and mental health, leading to severe stress or burnout. There is also now increasing recognition of the extent of moral distress and moral injury within the medical profession, which can have a very significant impact on doctors' health and wellbeing (see the BMA's report on moral distress in key resources). It is essential that doctors are alert to signs that their own health may be suffering and seek help and advice at an early stage. It is not a sign of weakness, but of strength, to admit to needing physical or emotional support at such times. In addition to local support services, the BMA's wellbeing service is available for all doctors (see information in key resources).



Is it appropriate for doctors to self-diagnose or self-treat?

No. Whilst it may be tempting for busy doctors to self-diagnose or prescribe for themselves, rather than take time out to see their registered doctor, this is high-risk both from a regulatory and a personal wellbeing perspective. Particular concerns include the temptation to extend oneself beyond one's competence and the possibility of denial in the face of serious illness. Doctors who self-prescribe may also fail to adequately document the treatment which could affect their future care if their treating doctor is unaware of the prescription. Of particular concern are self-prescriptions for medication where there is a risk of dependency, such as opiates or benzodiazepines. However, self-prescribing of regular medication is also problematic, particularly if this becomes frequent or routine, as opposed to a one-off situation where it is not possible to see another doctor. At paragraph 97 of *Good Medical Practice*, the GMC states that wherever possible doctors must avoid providing medical care to themselves. All doctors should be registered with a GP, outside their family or workplace, rather than treating themselves or informally asking a colleague to do so.

There may be exceptional cases where, due to circumstances outside of a doctor's control, self-treatment may be required, however they should be able and prepared to justify this decision. Where a doctor does self-prescribe, the GMC's guidance on prescribing (see key resources) states that they must make a clear record at the same time or as soon as possible afterwards including the reason the prescription was necessary and follow its advice on information and safe prescribing. The circumstances in which a doctor may prescribe controlled drugs for themselves are strictly restricted to when 'no other person with the legal right to prescribe is available to assess and prescribe without a delay' and 'emergency treatment is immediately necessary to avoid serious deterioration in health or serious harm.'

What considerations are relevant to treating patients who are doctors?

Doctors providing care for other healthcare professionals need to treat them as their patients, avoiding short cuts, informal 'corridor consultations', and unjustified assumptions. Doctor patients should be seen within formal consultations and offered proper explanations of what is involved in the investigation and management of their condition. They may already be well aware of such information, but should be allowed the opportunity to be the patient and be offered advice and support, if they want that, in the same way as other patients would be. The same principles apply when doctors are parents or carers of the patient.

Doctors who are patients are entitled to the same high standards of care and confidentiality. Unless the patient consents, or there is another lawful justification, healthcare professionals must not share information with others not directly concerned with their treatment. Sick doctors, particularly those with mental health and addictive problems, are often reluctant to seek medical advice due to concerns about confidentiality. Generally, they should be reassured that their confidentiality will be as closely protected as that of any other patient.

Out-of-area referrals should be considered, where possible, in cases where sick doctors have particular worries about confidentiality or being treated by colleagues who are acquaintances. As with all other patients, however, doctors' rights to confidentiality are not absolute and action needs to be taken where their health poses a threat to other people. Wherever possible, this should be discussed by the treating doctor with the sick doctor prior to disclosure.



Concerns about colleagues

What should I do if I have concerns about the health of a colleague?

Where doctors have concerns that the health of their colleagues may be preventing them from practising safely, they have a duty to take action, in the interests both of patient care and of their colleague's health. Not to intervene risks patient safety and can lead to further deterioration in the doctor's health and performance. Colleagues, particularly junior staff, are sometimes reluctant to speak out due to loyalty or for fear of damaging their own careers. However, the GMC emphasises the duty of all doctors to prevent risks to patients, including those arising from the ill health of colleagues. Early recognition and treatment considerably increase the chances of successful rehabilitation for the sick doctor. In Leadership and management for all doctors, the GMC states that 'You should be aware that poorly performing colleagues may have health problems and respond constructively where this is the case. You should encourage such colleagues to seek and follow professional advice and offer them appropriate help and support. You must not unfairly discriminate against colleagues because of an issue related to their health or a disability.'

What should I do if I have concerns about the conduct or performance of a colleague?

Where doctors have concerns about the performance of a colleague, they should ordinarily and wherever possible offer them support in the first instance. However there remains an overriding duty on doctors to promptly raise concerns where there exists a risk to patient care or safety. At paragraph 75 of *Good medical practice* the GMC states that 'If you have concerns that a colleague may not be fit to practise and may be putting patients at risk, you must ask for advice from a colleague, your defence body, or us. If you are still concerned, you must report this, in line with your workplace policy and our more detailed guidance on *Raising and acting on concerns about patient safety.'*



Key resources

BMA - Your wellbeing (bma.org.uk)

BMA – <u>Needlestick injuries and blood-borne viruses: testing adults who</u> <u>lack capacity</u>

BMA – Moral distress in the NHS and other organisations

GMC – Good practice in prescribing and managing medicines and devices

GMC – Leadership and management for all doctors

GMC – Raising and acting on concerns about patient safety



Patients' responsibilities

With the shift towards a partnership model of the doctor-patient relationship, came the notion that patients have certain responsibilities as well as rights, both in terms of maintaining their own health and when accessing healthcare. This notion of patient responsibilities is encapsulated in the NHS constitution in England, and The Charter of Patients' Rights and Responsibilities in Scotland, both of which set out what patients, the public, and staff are entitled to expect from the health service, but also what concomitant duties fall to those who use the NHS. Whilst doctors have the primary responsibility to make the doctor-patient relationship work, patients also need to play their part.

Patients' responsibilities

What responsibilities do patients have?

Under the NHS constitution certain responsibilities are assigned to patients, which are designed to ensure the smooth, fair, and effective running of the NHS: these are to:

- take personal responsibility for their own, and their family's good health and wellbeing;
- register with a GP practice;
- treat NHS staff and other patients with respect;
- recognise that violence, or the causing of nuisance or disturbance on NHS
 premises, could result in prosecution and recognise that abusive
 and violent behaviour could result in them being refused access to
 NHS services;
- provide accurate information about their health and condition;
- keep appointments or cancel within a reasonable time;
- follow the course of treatment that has been agreed;
- participate in important public health programmes, such as vaccination;
- ensure those close to them are aware of their wishes about organ donation; and
- give feedback, both positive and negative, about the experience and treatment and care received.

Although these expectations are not so clearly articulated in all parts of the UK, it is reasonable to assume that the same responsibilities should be assigned to all patients.

Engagement with their health and healthcare

How can I encourage more patients to be actively involved in maintaining their own health and wellbeing and in the development of our service?

The BMA is very keen to involve patients more in the development and use of healthcare services and our Patient Liaison Group has produced a toolkit to help GP practices to facilitate this (see key resources). Many of the suggestions can also be applied in secondary care.

How can I encourage patients to complete a course of treatment?

It can be frustrating when treatment goals are not achieved due to lack of compliance with an agreed treatment regime or because patients do not complete a course of medication. It is important, however, for doctors to be non-judgemental when discussing non-adherence and to encourage patients to be honest about their medicine taking.



Everyone has the right to refuse treatment, but it is important that reliable, accurate information is provided about the implications of doing so. This includes explaining the purpose of the medication and treatment and, where relevant, the need to complete a full course of treatment for it to be effective

Non-adherence is sometimes the result of confusion or misunderstanding, rather than a positive choice. Where they are available, written information sheets can help patients to understand their condition and medication and can serve as a useful reminder; information can often be forgotten particularly when given during a consultation which the patient may find stressful. Requests by patients to record the discussion, or to take notes, should be accepted as a way of helping the patient to comply with the agreed treatment regime (see section 2.5). Special attention should be given to those who need particular help such as older people with hearing difficulties or those for whom English is not their first language (see section 2.3).

It is important when discussing treatment options to take account of the patient's own preferences and concerns, and to modify the chosen approach if appropriate. A patient may prefer to take a less effective medication with fewer side-effects, for example, and taking these types of factors into account is likely to increase compliance with the treatment regime.

Can I refuse treatment to patients whose lifestyle choices, or failure to follow an agreed treatment regime, have contributed to their condition?

No. Asserting that patients have a responsibility to take steps to protect and maintain their own health and wellbeing does not mean that those who do not do so can be denied treatment. The GMC states clearly, in *Good medical practice* (paragraph 19), that:

'You must not refuse or delay treatment because you believe that a patient's actions or choices contributed to their condition.'

Patients who demonstrate violent, aggressive or racist behaviour

Can I refuse to treat patients who engage in violent, aggressive or racist behaviour?

Violent, aggressive, or racist behaviour towards healthcare staff is entirely unacceptable and healthcare professionals have a right to be protected from such behaviour. Employers have a duty of care to protect their staff and to put mechanisms in place to quickly and effectively manage any such situation that arises. In some circumstances, this may involve withholding treatment but there are also other steps that can and should be taken. BMA guidance on how to deal with discrimination from patients gives examples of the type of action that can be taken (see key resources).

Whether treatment can be withheld from a patient who acts in a violent, aggressive, or racist manner will depend on the reasons for the behaviour and the urgency of the patient's need. Sometimes the behaviour is caused by a patient's medical condition, mental illness, or medication. Identifying whether there is an organic cause for their behaviour is essential, particularly when patients appear to be acting out of character.

Patients who are threatening or racially abuse should not be denied urgent treatment or necessary immediate care, if this can be provided safely, but once the emergency situation has subsided this should be raised with the



patient who should be informed that such behaviour in future could result in treatment being withheld.

Where such behaviour does not arise as a result of underlying pathology, and treatment is not urgently required, we support a doctor's right to delay or refuse immediate treatment.

Patients who are violent can be immediately removed from a GP practice list and patients who meet the criteria can be provided with care in a secure environment via the special allocation service (see key resources). Some hospitals also have specific arrangements in place to treat patients who are known to be prone to violence.

Healthcare establishments should have a protocol for managing violent patients. This should be available to patients and should advise that information about violent patients may be shared with other healthcare professionals in the area, if this is necessary to protect staff from harm. In these circumstances, disclosure of information without consent will usually be justified in the public interest.



Key resources

BMA – How to manage discrimination by patients and their guardians/relatives

BMA – Patient and public involvement. A toolkit for GPs

BMA – Removing violent patients and the special allocation scheme

Department of Health and Social Care – The NHS Constitution for England 2021

NHS Inform (Scotland) – The Charter of Patients Rights and Responsibilities



Breakdown of the doctorpatient relationship

Doctors have particular responsibilities to try to make the relationship with patients work and to have the care of their patients as their first concern. Nevertheless, circumstances can arise when the relationship breaks down to such an extent that the best thing for all involved is to end the professional relationship and to pass the care of the patient to another doctor.

Decisions to end the professional relationship with a patient should never be made in the heat of the moment but only after careful thought and consideration of alternative options. Many patients who are misusing services or behaving inappropriately can change their behaviour if it is brought to their attention and they are informed of the consequences. Doctors must retain a high level of professionalism even in the face of difficult or confrontational behaviour from the patient.

Can I end the professional relationship with patients who make excessive demands?

It is not acceptable to end a professional relationship because of the resource implication, or time commitment, of providing a patient with necessary and appropriate care or treatment. Updated guidance for GP practices, from NHS England (see key resources), however includes 'unnecessarily persistent or unrealistic service demands that cause disruption' amongst inappropriate and unacceptable behaviour by patients that could, in some circumstances, lead to a patient being removed from a practice list.

Can I end a professional relationship with a patient who makes a complaint about me?

The GMC's guidance Ending your professional relationship with a patient, is clear that:

You should not end a professional relationship with a patient solely because of:

- a. a complaint the patient made about you or your colleagues.
 You must make sure that any complaints or concerns raised by the patient are responded to promptly, fully and honestly (*Good medical practice*, paragraph 46)
- b. the resource implications of the patient's care or treatment.'

Complaints raised through the appropriate mechanisms should be handled sensitively and objectively and can provide learning for both healthcare professionals and patients. The fact that a patient has made a complaint is not in and of itself grounds for ending the professional relationship. Being the subject of a complaint can, however, have a significant emotional impact on doctors, particularly if complaints are unfounded, repeated, vexatious, or make personal attacks on them. In such circumstances the complaint may be indicative of a significant breakdown in the relationship, where mutual trust and confidence has been lost. In these cases the best option for all concerned may be to end the professional relationship. It would be the irretrievable breakdown of the relationship, not the complaint, that would be the reason for ending the relationship, and this should be made clear to the patient.



Managing a breakdown in the doctor-patient relationship

What should I do if my relationship with a patient has broken down?

The GMC's guidance on *Ending your professional relationship with a patient*, states that:

- '6. It may be reasonable to end a relationship immediately in certain circumstances. For example, primary care regulations and contracts allow for the immediate removal of patients from practice lists if a patient has been violent or behaved in a way that has caused other people to fear for their safety. You must follow local or national guidance and regulations.
- 7. In other circumstances, before you end a professional relationship with a patient you should:
 - a. tell the patient that you are considering ending the relationship and explain the reasons why
 - b. do what you can to restore the professional relationship.
 This could include setting expectations for the patient's future behaviour.
 - c. discuss the situation with an experienced colleague or your employer, or contracting body.
- 8. You must seek advice from a safeguarding lead if you are concerned that ending a relationship with a patient could leave them, or someone close to them, at risk of significant harm.'

Doctors must also be 'satisfied that your reason for wanting to end the relationship is fair and does not discriminate against the patient.'

All discussions or communications with the patients should be carefully documented in the medical record. This should be factual and objective and should not include anything that could unfairly impact on the patient's future treatment or professional relationships.

What should I do if I want to remove a patient from my practice list?

In some circumstances, where the relationship has broken down with one GP, it may be possible for them to see other GPs in the practice as an alternative to removing them from the practice list. Removing patients from a practice list is rare, but where the relationship has irretrievably broken down, BMA guidance, *Removing patients from your practice list*, recommends the following action is taken.

- 1. Where practices intend to remove a patient because of the breakdown of the doctor-patient relationship, you should first consider discussing the problem with an independent party, eg LMC secretary.
- 2. Issue a warning to the patient, preferably in writing, giving the reasons for the possibility of removal. Warnings are valid for 12 months and a written record must be retained.
- 3. Send a written notice to the PCO or NHS England, giving the patient's name, address, date of birth and NHS number. (In Wales, the Local Health Board sould be notified; in Scotland, the Community Health Index see key resources; and in Northern Ireland, the Health and Social Services Board.)



Do I need to find another doctor for the patient to see?

Doctors have a duty of care to their patients and cannot simply abandon them. In secondary care, arrangements need to be made for another doctor to take over the patient's care before responsibility can be relinquished, to ensure the patient's treatment is not jeopardised and they continue to have the advice and care they need. In primary care, patients can be transferred to another GP in the practice, if available, or apply directly to another practice in the area or contact the relevant organisation to be allocated to another practice (ICS in England, Local Health Board in Wales, Business Service Organisation in Northern Ireland, and Practitioner Services Team in Scotland).



Key resources

BMA – Removing patients from your practice list

GMC – Ending your professional relationship with a patient

NHS England – <u>Primary Medical Care Policy and Guidance Manual (PGM) – updated May 2022</u>

NHS Scotland – How to remove patients | National Services Scotland (nhs.scot)



Non-typical relationships and dual obligations

What if I do not work in a 'typical' doctor-patient relationship?

Not all professional relationships in medicine are primarily therapeutic. Doctors can work in a range of roles where they owe duties to other parties. Doctors may, for example, act as impartial and independent examiners with accountability to commissioning organisations. These include doctors working as examiners for insurance companies or employed by the state to assess eligibility for health-related benefits. In these circumstances, a doctor's primary obligation is not to the wellbeing of the individual patient but to the employing or commissioning body.

Doctors working in these roles must clearly explain the nature of the relationship to their patients. They must be clear that any tests undertaken, or information gleaned from the examination, are not for the purposes of the patient's healthcare. Although not an ordinary therapeutic relationship, in our view doctors retain some obligations to patients in these circumstances. If, for example, they identify health information important to the patient, this should ordinarily be disclosed to them. How such a situation will be managed should be discussed with the patient and the commissioning agent prior to the examination.

Access to medical reports

Do patients have the right to see medical reports written about them?

The Access to Medical Reports Act 1988 and Access to Personal Files and Medical Reports (Northern Ireland) Order 1991 give patients the right to see medical reports written about them for employment or insurance purposes, by a doctor whom they usually see in a 'normal' doctor-patient capacity. This includes reports written by the patient's GP or a specialist who has provided care. This right can be exercised either before or after the report is sent. Patients have the right to highlight any disagreement with matters of fact recorded in the report, and to append their disagreement to the report, or to withdraw their consent for the release of the information.

Medical reports written by independent medical examiners are excluded from this legislation, and there has previously been debate and contention about the extent to which occupational health physicians, for example, were subject to the legislation. All registered doctors, however, are obliged to follow GMC guidance (see key resources) which states that individuals must be offered the opportunity to see a report written about them for employment or insurance purposes before it is sent unless:

- they have already indicated they do not wish to see it;
- disclosure would be likely to cause serious harm to the patient or anyone else; or
- disclosure would be likely to reveal information about another person who does not consent.



Managing dual obligations

What happens where I have clear obligations both to patients and to a third party?

Some doctors, such as those working in detention settings or the armed forces, can have what are known as 'dual obligations' with significant duties both to patients and another party. Ethical obligations to patients are not diminished in these circumstances. Doctors cannot be obliged by contractual or other considerations to compromise their professional independence. They must make an unbiased assessment of the patient's health interests and act accordingly. Although there is not always tension here, there may be instances when their role will not be in the interests of the individual, and conflicts, real or perceived, may arise.

What are the guiding principles for healthcare professionals with dual loyalties?

The conduct of healthcare professionals with dual obligations should accord with the ethical standards of other practitioners. In addition to the basic duties on all healthcare professionals, those with dual loyalties should:

- remember their duty of care for individuals, even where health
 assessments take place for reasons other than the provision of treatment;
- ensure that patients are informed of the nature and extent of any dual obligations and the impact they may have on their rights and interests;
- provide care that is, at least, of a comparable standard to that provided in the community;
- seek informed consent, even if the law does not require it to be obtained;
- respect the rights of patients to have access to appropriate information about treatment options;
- respect patient confidentiality and inform patients at the time they
 provide information if it will be used for purposes other than their care –
 they should also know what those purposes are likely to be and whether
 they can opt out;
- respect patients' human rights and be sensitive to the ways in which they may be compromised;
- maintain robust standards of professional and clinical independence;
- identify where services or conditions are inadequate and may pose a threat to health and raise concerns as appropriate;
- be sensitive to the needs of patients with vulnerabilities and guard against inappropriate forms of discrimination; and
- be able to justify any departure from accepted ethical principles or guidelines.



Key resources

BMA – Access to medical reports

BMA – Ethical issues in forensic and secure environments

BMA – Ethics toolkit for armed forces doctors

GMC – <u>Disclosing information for employment, insurance and similar</u>

<u>purposes – ethical guidance</u>



3

Consent and refusal by adults with decision-making capacity



Contents

3.1 Introduction to consent and refusal59
3.2 Capacity to consent62
3.3 Sharing information with patients64
3.4 Who is responsible for seeking consent?68
3.5 Refusal of consent69
3.6 Advance care planning70
3.7 Consent for emergency treatment72
3.8 Compulsory treatment under mental health legislation73
3.9 Consent for research74
3.10 Consent for teaching purposes75



Introduction to consent and refusal

This guidance applies across the UK, and specifies where the law differs between nations. It applies only to adults who have the capacity required to give or withhold consent - that is, those aged 18 or over in England, Wales, and Northern Ireland and 16 or over in Scotland. For information on decision making for children and young people (aged under 18, in England, Wales, and Northern Ireland, and under 16 in Scotland), and on adults who lack capacity, see our separate guidance (see key resources).

When is it necessary to seek patient consent?

Doctors must obtain consent from patients who have the capacity to give it any time they wish to initiate an examination, treatment, or any other intervention. They must also seek consent when involving patients or volunteers in teaching or research (see sections 3.9 and 3.10).

The only exceptions to this are in emergencies where it is not possible to obtain consent (see section 3.7), or when the law prescribes otherwise, such as when compulsory treatment for a patient's psychiatric disorder is authorised by mental health legislation (see section 3.8). (Mental health legislation cannot authorise non-consensual treatment for physical conditions that are not directly related to a psychiatric disorder.)

Proceeding with treatment without valid consent may put the patient at risk of harm. It also leaves the doctor who is carrying out the procedure and, where different, the doctor who sought consent at risk of criticism and, potentially, legal and/or regulatory sanctions.

What is required for consent to be considered valid?

In order for consent to be valid, patients must:

- have the capacity to make the decision;
- have been offered sufficient information to make an informed decision;
- be acting voluntarily and free from undue pressure; and
- be aware that they can refuse.

How should consent be obtained?

Consent can be explicit or implied. Explicit or express consent is when a person actively agrees, either orally or in writing. Implied consent is when consent is signalled by the behaviour of a patient, for example by opening their mouth to allow a doctor to examine their throat. This is not a lesser form of consent, provided the patient genuinely knows and understands what is being proposed and is aware that they have the option to refuse.

The General Medical Council (GMC) at paragraph 5 of its guidance *Decision making and consent*, advises that doctors can apply their own professional judgement about the most appropriate way to seek consent which will be dependent on the specific circumstances of each decision, including:

- 'a. the nature and severity of the patient's condition and how quickly the decision must be made
- b. the complexity of the decision, the number of available options and the level of risk or degree of uncertainty associated with any of them
- c. the impact of the potential outcome on the patient's individual circumstances
- d. what you already know about the patient, and what they already know about their condition and the potential options for treating or managing it
- e. the nature of the consultation.'



The GMC also advises, at paragraph 7, that whilst it would be reasonable for a doctor to rely on a patient's non-verbal consent even for some routine, quick, minimally or non-invasive interventions, doctors should still:

- 'a. explain what is going to be done and why
- b. make clear the patient can say no, and stop immediately if they do
- c. be alert for any sign that the patient may be confused or unhappy about what you are doing.'

Can family members give consent on behalf of an adult patient with capacity?

No. Family members do not have the legal authority to give consent on behalf of an adult patient with capacity. Where the patient has appointed a family member as a health and welfare attorney to make decisions on their behalf (see section 3.6) this only comes into force when the patient loses capacity.

Does consent always need to be in writing?

No. Written consent is only legally required for a small number of treatments (such as some forms of fertility treatment), it is often advised in other circumstances, particularly where the procedure is very invasive or entails more than minimal risks. Doctors should familiarise themselves with the latest clinical guidance in their area of practice. Consent forms can be used to document that discussions about the procedure have taken place. However, consent forms are evidence of the consent process, rather than consent itself; a patient genuinely understanding what is being proposed is more important than how consent is recorded.

What should be recorded in a patient's medical records?

Details of the discussions that have taken place with a patient, and any other relevant people, should be recorded in the patient's medical records. This should usually include discussions about the treatment options, including potential harms and benefits of any treatment, any specific concerns the patient had and any other information that was given to them.

How long is consent valid for?

Consent should be a continuing process, rather than a one-off decision. Patients can change their mind about treatment at any time. Before beginning any treatment, doctors should check that the patient still consents. This is particularly important if:

- a significant length of time has passed since the patient agreed to the treatment:
- there is new information available;
- there have been any significant changes to the patient's condition; or
- the process of seeking consent had been delegated to a colleague.

It is important that patients are given continuing opportunities to ask further questions and to review their decisions and are kept informed about the progress of their treatment or care.



Can a competent patient refuse treatment?

Yes. Competent adult patients are entitled to refuse treatment, even if that will result in their death or serious harm (see section 3.5 and for 16 and 17 year olds see our separate guidance on children and young people - see key resources). The only exception to this is where the law prescribes otherwise, such as when compulsory treatment for the patient's psychiatric disorder is authorised by mental health legislation (see section 3.8).

Do I have to provide treatment which I do not think is clinically appropriate for the patient?

If a patient asks for treatment that you do not think would be clinically appropriate for them, you should discuss their reasons for requesting it with them. Any significant factors for the patient should be explored further, including non-clinical factors such as their beliefs or views. Following this, if you still consider that the treatment is not clinically appropriate, you do not have to provide it. However, the reasons for this should be explained clearly to the patient, as well as other options available to them, including seeking a second opinion.

What consent should be sought when a healthcare professional has suffered a needlestick injury or other occupational exposure to a patient's blood or bodily fluid?

If they have capacity, consent should be sought from the patient to test them, or an existing sample, for serious communicable diseases. If the patient refuses to consent no test should be carried out. For information on testing of patients who lack capacity in the event of a needlestick injury, see the BMA's separate guidance on needlestick injuries.



Key resources

BMA – Adults with incapacity Scotland toolkit

BMA – Children and young people toolkit

BMA – Mental Capacity Act toolkit

BMA – Mental capacity in Northern Ireland toolkit

Department of Health and Social Care (DHSC) – Reference guide to

consent for examination or treatment

GMC – Decision making and consent



Capacity to consent

Are adults presumed to have capacity to consent?

Yes. It is a fundamental principle of the law in the UK that adults have the right to make decisions on their own behalf and are assumed to have the capacity to do so. This means that it is never for an adult to prove their own capacity. Where a person intends to take steps on the basis that an adult lacks capacity to make the relevant decision, that person must be able to explain why they consider that they are allowed to do so, including why the adult can be said to lack capacity.

You must not assume that a patient lacks capacity because they are suffering from a mental disorder or impairment, or any medical condition or disability, because of their age, appearance or views, or because you consider the decision to be unwise or irrational. If, however, their decision is clearly contrary to previously expressed wishes, or based on a misperception of reality, this may be indicative of a lack of capacity and should be investigated further.

You must not assume that because a patient lacks capacity to make a decision on a particular occasion, they lack the capacity to make a decision at any other time. Some patients may also have capacity to make some decisions about their healthcare but not others; the difficulty, complexity, or seriousness of the decision should be one of the factors taken into account when assessing the individual's capacity to make that decision. More information about assessing capacity can be found in our mental capacity guidance (see key resources).

It is important to note that despite the presumption of capacity from the age of 16, the situation regarding refusal of treatment is different for 16 and 17-year olds. For information about decision making by and on behalf of those aged 16 or 17, see our guidance on children and young people (see key resources).

How should I assess whether someone has the capacity to consent?

Where there are grounds to question whether the patient has the capacity to make the decision in question, an assessment is required. This is a matter for clinical judgement, guided by professional practice and subject to legal requirements.

To demonstrate capacity to consent to treatment, individuals should be able to:

- understand the information relevant to the decision;
- retain the information relevant to the decision;
- use or weigh the information; and
- communicate the decision (by any means).

In England, Wales, and Northern Ireland, a person lacks capacity if their inability to do these things is caused by an impairment or disturbance in the functioning of the mind or brain.



What should I do if I suspect that a patient lacks capacity?

For information on how to proceed where there are grounds to doubt a patient's capacity, healthcare professionals should refer to our guidance on mental capacity (see key resources).



Key resources

BMA – Mental Capacity Act toolkit

BMA – Adults with incapacity Scotland toolkit

BMA – Mental capacity in Northern Ireland toolkit

BMA – Children and young people toolkit



Sharing information with patients

What information should I share with patients to obtain their consent?

For patients to make decisions about their treatment and provide valid consent, doctors need to provide them with sufficient, clear and accurate information about any proposed course of action or treatment option. This includes information about:

- the purpose of the investigation or treatment;
- details and uncertainties of the diagnosis;
- options for treatment, including the option of no treatment;
- likely benefits and probabilities of success for each option;
- risks and potential side-effects, and adverse outcomes including the treatment not working;
- the name of the doctor with overall responsibility for their care;
- a reminder that a patient can change their mind about having the treatment at any time;
- reasons for any recommended treatment options; and
- if relevant, any foreseeable problems that could come to light while the patient is unconscious.

The discussions you have with patients should be tailored according to the nature and complexity of the proposed course of action, and the level of risk associated with it. They should also be tailored according to the individual concerns, wishes, and values of each patient and their understanding of their condition and prognosis. For example, if the proposed treatment carries a potential risk of harm that you believe the patient would consider to be serious in their circumstances, you must tell the patient, even if you think it is very unlikely to occur. You should also tell patients about less serious side-effects or complications if they occur frequently, or if you think the patient may attach particular significance to them.

In March 2015, the UK Supreme Court (<u>Montgomery v Lanarkshire Health Board</u>) clarified that doctors must 'take reasonable care to ensure that the patient is aware of any material risks involved in any treatment, and of any reasonable alternative or variant treatments'. A 'material risk' is one in which 'a reasonable person in the patient's position would be likely to attach significance to the risk, or the doctor is or should reasonably be aware that the particular patient would be likely to attach significance to it'.

Although this reflects existing good practice, it is a significant judgment in that it means that doctors can no longer rely on the support of a responsible body of medical opinion ('the Bolam test') in deciding what information they should provide to patients. Instead, they must provide information about any risk to which the individual patient would attach significance.

When seeking consent, doctors therefore need to ask themselves the following questions.

- Is the patient aware of any risks relevant to their decision regarding the proposed treatment?
- Is the patient aware of any reasonable alternatives and their associated risks and benefits?
- Have I taken all reasonable measures to ensure that I have presented this information in a form the patient understands?
- Is the patient aware that they can refuse to have the treatment?



In July 2023, the Supreme Court in McCulloch v Forth Valley Health Board clarified the meaning of the words 'reasonable alternative or variant treatments' in Montgomery v Lanarkshire Health Board. The Court was asked to determine whether a particular treatment is a 'reasonable alternative' is a matter of professional skill and judgement to be assessed by applying the professional practice test, in other words, the 'Bolam test', or whether it is a matter to be determined by reference to the circumstances, objectives, and values of the individual patient.

The Court unanimously held that whether a treatment is a reasonable alternative is to be determined by the application of the Bolam test.

The Court confirmed that:

- a doctor cannot simply inform a patient about the treatment option or options that they prefer;
- once a range of reasonable treatments have been identified, absent any indication from the patient to the contrary, the doctor must explain all of those alternatives (and the risks involved) to the patient. However, a doctor is not obliged to tell a patient about treatments which the doctor does not consider to be reasonable to be judged by applying the Bolam test; and
- a doctor is not obliged to tell a patient about treatments that the doctor does not consider reasonable (applying the Bolam test) even where the doctor is aware of an alternative body of opinion which considers the treatment to be reasonable.

Should I withhold any information?

No. You should not withhold any information the patient needs to make a decision, including when a relative or carer asks you to. Failure to provide sufficient relevant information could be challenged in law.

There is some limited scope for doctors to withhold information where they have a reasonable belief that providing the information would cause the patient serious harm. In the case of Montgomery, the Supreme Court made clear, however, that this exception should not be abused; it is designed to protect patients from serious harm, not to prevent them from making a choice the doctor considers to be contrary to their best interests.

In some circumstances it may be appropriate to provide relevant information over a period of time, rather than providing it all at the same time. In such cases it should be clear from the medical record what information has already been shared, what information still needs to be shared, why some information was withheld and when and how the patient will be provided with it.

How should I share information with patients?

The GMC emphasises the importance of listening to patients and a shared decision-making process. In this process, the information your patients share with you, is as important as the information you give them.



Patients should be involved as much as possible in decisions about their own health and care, and should be given information about their treatment options in a way that they can understand. Doctors should take all reasonable steps to maximise patients' ability to understand, consider options and make a decision. This includes:

- taking time to understand the patient's values, wishes, preferences, and knowledge of their own condition;
- using clear and consistent language when discussing risks of harm and potential benefits;
- encouraging patients to ask questions;
- supporting patients with additional needs to have the time and any reasonable adjustments to make a decision;
- offering a record of your discussions if the patient may have difficulty retaining information;
- giving the patient time to reflect, before and after they make a decision;
- where appropriate, involving other members of the healthcare team in discussions;
- giving information that the patient may find distressing in a considerate way;
- sharing information at a time and place when you think the patient is most likely to be able to understand and retain it;
- supporting discussions with accurate written material, or visual or other aids;
- providing the opportunity for patients to discuss their options with others;
 and
- considering whether the patient might need more time with you or the healthcare team.

Before making a decision, you must check that your patients have understood the information they have been given and the language that you have used, or whether they need any more support to make a decision. You should ensure the patient is aware of any time limit on making their decision.

How should I answer any questions my patients may have?

Doctors should respond honestly and accurately to any questions patients may ask them. This includes discussing the nature and extent of any uncertainty regarding the clinical effect of a particular intervention.

If you are unable to answer a question, where possible you should find out the answer by consulting another professional or resource — or explain to the patient if there is an inherent uncertainty.

What if a patient does not want to know the information?

If a competent patient does not want to know the information, or make a decision, about their treatment, you should try to find out why and whether you can do anything to support them. Ultimately, however, patients retain the right not to be informed of the risks of a procedure — if a patient does not want to know, doctors are under no obligation to tell them.

Nevertheless, a minimum amount of basic information may need to be given in order for consent to be considered valid. Without basic information, patients may be unable to make a valid choice to delegate responsibility for treatment decisions to doctors. The amount of basic information needed depends upon the individual circumstances, the severity of the condition and the risks associated with the treatment.



You should explain why it is important for them to make an informed decision, and the potential consequences of them choosing not to receive information including, in some circumstances, being unable to proceed with the treatment.

Patients who refuse information should be advised that information can be provided at any time, should they change their mind, and a note should be made on the medical record that the patient has refused information.

What if I am not able to share information sufficiently, due to time and resource constraints?

If you are not able to share information sufficiently with your patients, because of pressures on your time or limited resources, you should consider the role of other members of the healthcare team in assisting you (see section 3.4). This might involve them gathering information and answering questions on your behalf. You should also consider other sources of information that are available such as patient information leaflets or support groups.

If there are factors outside your control which are compromising your patients' ability to make informed decisions, you should raise these concerns with your employer. Patients need to be given sufficient information for their consent to be valid.



Key resources

DHSC – Reference guide to consent GMC – Decision making and consent



Who is responsible for seeking consent?

Whose responsibility is it to seek consent?

Clinical, legal and professional responsibility for ensuring that valid consent has been obtained before treatment is provided rests with the person carrying out the procedure. In some circumstances this may be delegated to a colleague, provided that person has the necessary knowledge, skills, and experience.

The GMC is clear that the doctor undertaking an investigation or providing treatment, is responsible for ensuring they have valid consent or other authority before commencing the procedure or treatment.

Part of the consent process may be delegated to other members of the team, but the doctor carrying out the treatment must be sure the person they are delegating to:

- is suitably trained and qualified;
- has sufficient knowledge and skills; and
- feels competent to carry out the tasks requested.

Your decision about whether delegating is appropriate should depend on the complexity of the intervention, the level of uncertainty surrounding the outcome, your relationship to the patient and any concerns the patient may have. If you are the doctor being delegated to, you must make sure you have sufficient knowledge and expertise to obtain consent from the patient.

What if I am asked to seek consent but do not feel competent to do so?

It is your responsibility to ensure you have sufficient knowledge and expertise to provide information, answer questions, and seek consent for common procedures in the specialty within which you are working. If, in a particular case however, you do not feel that you have sufficient information or expertise to comply with the request, you should inform the person who will be carrying out the procedure. You should not comply with a request to seek consent if, having raised these concerns, appropriate support is not provided.

What if the person I ask to seek consent raises concerns about doing so?

If you are informed by the individual tasked with seeking consent that they do not have the necessary knowledge or skills to comply with the request, you must ensure that support is provided, or make alternative arrangements, to ensure that valid consent is obtained.

If you delegate responsibility for seeking consent to someone who does not have the necessary knowledge and skills, you must accept overall responsibility for any failings in the consent process.



Key resources

DHSC – Reference guide to consent GMC – Decision making and consent



Refusal of consent

Can patients refuse to consent to treatment?

Yes. Competent adult patients can refuse to consent to any treatment except where compulsory treatment for the patient's psychiatric disorder is authorised by mental health legislation (see section 3.8). The situation is different for patients under the age of 18; for more information on this see the BMA's guidance on children and young people (see key resources).

Doctors must respect a patient's decision to refuse treatment, even if they do not agree with it or when it could lead to permanent injury or death. For example, a Jehovah's Witness can refuse a blood transfusion even where this is essential for survival. Providing treatment without valid consent, and in the face of a competent refusal, would leave the doctor open to legal and professional sanctions.

A refusal of treatment should not be interpreted as a refusal of all treatment or care. It is essential that steps are taken to keep the patient comfortable and that any symptoms or distress are appropriately managed.

Can patients refuse food and fluids?

Yes. Competent adult patients can refuse food and fluids – whether provided orally or by tube (clinically-assisted) – and such refusals must be respected. It should be made clear to such patients, however, that they can change their minds and accept food and/or fluids at any time.

Whilst a valid and applicable advance decision to refuse clinically-assisted nutrition and hydration will be legally binding once a patient loses capacity (see section 3.6), an advance refusal of oral feeding (which forms part of 'basic care') will not be. Oral feeding should continue to be offered to, but not forced upon, all patients who are capable of swallowing safely.

Do patients need to justify their decision to refuse consent?

No. Patients are not required to justify their decision to refuse consent, but healthcare professionals should seek to ensure that patients base their decisions on accurate information and that they have corrected any misunderstandings. Patients also need to know if refusing treatment now will limit their future options.

Doctors must not put pressure on patients to decide in a particular way, but should allow them time to consider a decision with potentially serious consequences.



Key resources

BMA – Children and young people toolkit



Advance care planning

Can a patient plan for future treatment once capacity is lost?

Yes. It is a good idea to encourage patients to think about what they would want to happen in the future if they are unable to express views about treatment for themselves. This is particularly important where loss of capacity is a foreseeable possibility, or where the patient may find it difficult to make decisions in the future. It is also useful for patients to consider these issues in circumstances where decisions may need to be made quickly at a later stage, or when they have a condition that will affect the length or quality of their life.

Doctors should take all reasonable steps to plan for foreseeable changes in a patient's capacity to make a decision, and help patients to make decisions at a time when they are able to do so. They should encourage patients to think about what they might want in the event of different outcomes, and to discuss this with the healthcare team and those close to them. These discussions should cover:

- the patient's wishes, concerns or personal beliefs in relation to their future care;
- any treatments they would want provided, or to refuse, and under what circumstances; and
- any interventions that might become necessary during an emergency.

Doctors must record the discussions in the patient's medical record and document any views or decisions the patient expresses.

Can patients request treatment in advance?

Advance requests for treatment are not legally binding, but they should be taken into account in assessing whether the treatment would be in the patient's best interests. It is, however, part of a doctor's duty of care to take reasonable steps to keep a patient alive where that is the patient's known wish (*R* (on the application of Burke) v General Medical Council (2005)).

Can patients refuse treatment in advance?

Yes. If a patient has clear views about treatments they would want to refuse, and the circumstances in which they would want to refuse them, they should be informed of the possibility of making a formal advance decision to refuse treatment (ADRT), known as an advance statement in Scotland. For more information see our mental capacity guidance (see key resources).

Can patients appoint someone to make decisions on their behalf?

Another option for patients who wish to plan for a future loss of capacity is to formally appoint someone as an attorney with the power to make health and care decisions on their behalf (in England and Wales these are called lasting powers of attorney or LPAs and in Scotland they are called welfare attorneys). In England, Wales, and Scotland, where the appropriate process has been followed, the attorney will be the lawful decision maker. Currently, in Northern Ireland, nobody can give consent on behalf of an adult who lacks capacity.



More information is available in our separate guidance on mental capacity (see key resources).

Key resources

BMA – Adults with incapacity Scotland toolkit

BMA – Mental Capacity Act toolkit

BMA – Mental capacity in Northern Ireland toolkit

DHNI – For now and the future. An advance care planning policy for adults in Northern Ireland

NHS England – Universal principles for advance care planning

NHS Wales – Advance and future care plans

Scottish Government – <u>Anticipatory care planning</u>



Consent for emergency treatment

Does consent need to be sought for emergency treatment?

Yes, if the patient has the capacity to give consent.

If the patient is unable to give consent, can treatment be provided in an emergency situation?

In an emergency, where consent cannot be obtained, doctors should provide treatment that is immediately necessary either to preserve life or to prevent a serious deterioration in the patient's condition. The only exception to this is where there is clear evidence of a valid and applicable advance decision to refuse the treatment in question.

In England, Wales, and Northern Ireland, emergency treatment does not have to be restricted to what is immediately necessary. It can also include steps that are in the patient's best interests to prevent deterioration in order to ensure that recovery is an option. It is unclear, however, how far the principle of necessity applies in Scotland and so a section 47 certificate of incapacity should be issued as soon as possible. For more information, see the BMA's guidance on mental capacity (see key resources).

Where decisions can reasonably be delayed until such time as the adult is likely to regain capacity, or to permit an assessment of capacity and discussion with those close to the patient, then they should be.



Key resources

BMA – Mental Capacity Act toolkit

BMA – Adults with incapacity Scotland toolkit

BMA – Mental capacity in Northern Ireland toolkit

GMC – Decision making and consent



Compulsory treatment under mental health legislation

Can treatment be provided to a patient without seeking consent if they are detained under mental health legislation?

Mental health legislation permits doctors to treat a patient compulsorily for a mental illness, without their consent. This includes treatment for physical conditions arising directly from a psychiatric condition such as forced renutrition in patients with anorexia nervosa or treating wounds self-inflicted as the result of a mental disorder. However, it is still good practice to explain to the patient the treatment that will be provided, and where possible, to seek their agreement.

Compulsory treatment can only be authorised under mental health legislation if it is treatment for the mental illness and the legislation specifically excludes imposing treatments for other physical conditions. Consent is still, therefore, required for other forms of treatment, even if the patient is detained under mental health legislation.

Legislation has been passed in Northern Ireland that will remove the ability to provide compulsory treatment for mental disorders for patients who have capacity; these provisions have not yet come into force.

Are advance decisions overruled when a patient is detained under mental health legislation?

Advance decisions can be overruled if the individual is being treated compulsorily under mental health legislation, with regards to treatment for a mental illness. A valid and applicable refusal of treatment for conditions that are not covered by the mental health legislation will still be binding.



Key resources

GMC - Making decisions and consent



Consent for research

Is separate consent required for research procedures?

Yes. Doctors must ensure that patients asked to consider taking part in research are given clear information, presented in a way they can understand. Patients should be made aware that they are being asked to take part in a research project and that the results are not predictable. Adequate time must be given for reflection prior to the patient giving consent. Where patients do not wish to receive full information about the research, this may affect the doctor's decision to involve them.

What information should be provided to obtain valid consent to participate in research?

Information should preferably be provided in writing and should be approved in advance by a research ethics committee. It should include:

- the purpose of the research and what it involves;
- information about research-related procedures particularly invasive procedures;
- the probability of random allocation to treatment, if appropriate;
- the fact that patients can withdraw from the research at any time, without penalty or any adverse effect on the care they receive (but that once data or samples have been anonymised, it will no longer be possible to withdraw consent for their use);
- any financial arrangements in place, such as for covering patients' expenses and compensation in the event of trial-related injury;
- information about confidentiality and the possibility of access to confidential notes by third parties (such as regulatory authorities, auditors, or ethics committees); and
- what, if any, information they can expect to receive about the research findings and conclusions.

Is consent required for the use of human tissue for research?

Under the Human Tissue Act 2004 (England, Wales, and Northern Ireland) if the samples are anonymised and the research has been approved by a research ethics committee, consent is not required. In other circumstances, consent must be obtained and documented before the storage and use of a living person's organs, tissues, or cells, for the purpose of research. In addition, where the intention is to perform DNA analysis, the Act's requirement for consent extends to Scotland.

The Human Tissue (Scotland) Act 2006 does not cover the use of tissue from living individuals. Research ethics committees may, however, require consent to be obtained where the tissue is used in identifiable form.



Key resources

 $\mathsf{GMC} - \underline{\mathsf{Good\ practice\ in\ research}}$

GMC – Consent to research



Consent for teaching purposes

Is it necessary to seek a patient's consent for medical students or other observers to be present during a consultation or treatment?

British Medical Association

Yes. The doctor carrying out the consultation should explain to the patient that an observer would like to sit in on the consultation, who that person is and why they would like to observe. Patients should feel able to say no, knowing that it will not impact on their treatment in any way.

Wherever possible, patients should be given the option of considering the request before the arrival of the observers.

Is specific consent required to teach practical procedures on a patient who has been anaesthetised?

Yes. Before any anaesthetic is given, specific consent must be obtained from the patient to carry out any practical procedures on them for teaching purposes.

Is it necessary to seek consent from patients for the use of visual and audio recordings of procedures, for teaching purposes?

Yes. Doctors must obtain consent from the patient prior to a recording being made and for its subsequent use for teaching purposes.

Patients may withdraw their consent to the use of visual and audio recordings for teaching purposes at any time. If they do so, the recordings must be erased.

What type of consent is required for the use of human tissue for educational purposes?

Consent is not required for the storage and use of material from living individuals for teaching purposes, provided it is anonymised. The use of identifiable samples for teaching requires consent.



Key resources

GMC - Making and using visual and audio recordings of patients



4

Mental Capacity Act -England and Wales



Contents

4.1 Introduction78
4.2 Capacity and incapacity79
4.3 Basic principles80
4.4 Assessing capacity82
4.5 Best interests85
4.6 Supported decision making87
4.7 Lasting powers of attorney88
4.8 Court of Protection and court appointed deputies90
4.9 Independent Mental Capacity Advocates92
4.10 Advance decisions to refuse treatment94
4.11 Treatment in emergency97
4.12 Treatments requiring special safeguards98
4.13 Restraint and restrictive measures 100
4.14 Care and treatment amounting to deprivation of liberty – the Deprivation of Liberty Safeguards regime (DoLS)
4.15 Research
4.16 Relationship with the Mental Health Act 107
4.17 Dispute resolution
4.18 Confidentiality and information sharing111



Introduction

The Mental Capacity Act 2005 (MCA) provides a legal framework for decision making on behalf of adults aged 16 and over who lack capacity to make decisions on their own behalf.

The Act applies to decisions taken on behalf of people who permanently or temporarily lack capacity to make such decisions themselves, including decisions relating to medical treatment. All doctors working with adults who lack, or who may lack, capacity must be familiar with both its underlying principles and its basic provisions.

Under the MCA, an action or intervention will be lawful (that is, healthcare professionals will enjoy protection from liability) where the decision maker has a reasonable belief that the individual lacks capacity to consent to what is proposed, and the action or decision is in their best interests. In relation to medical treatment, it is applicable not only to an episode of treatment, but also to those necessary ancillary procedures such as conveying a person to hospital.

There are limits to these powers. A valid and applicable advance decision to refuse treatment, or a valid decision by an attorney or a court-appointed deputy, would take precedence. The MCA also sets limits on the extent to which the freedom of movement of an adult who lacks capacity can be restricted. An adult who lacks capacity can only be restrained where there is a reasonable belief that it is necessary to protect them from harm and the proposed action is proportionate to the risk; where any restriction amounts to a deprivation of liberty, it is only lawful when the appropriate authorisation is in place.

The MCA is accompanied by a statutory Code of Practice providing guidance on how it should be used. Certain people have a legal duty to have regard to the Code of Practice, including anyone acting in a professional capacity or being paid for their work with people who may lack capacity. It is therefore essential that healthcare professionals are familiar with the Code of Practice.



Key resources

Care Quality Commission – <u>About the Mental Capacity Act</u>
Department for Constitutional Affairs – <u>Mental Capacity Act 2005 Code</u>
of <u>Practice</u>

Mental Capacity Act 2005

Social Care Institute for Excellence – <u>Mental Capacity Act (MCA)</u> <u>guidance</u>



Capacity and incapacity

What is capacity?

Decision-making capacity refers to the everyday ability we possess to make decisions or to take actions that influence our lives, from simple decisions about what to have for breakfast, to complex decisions about serious medical treatment. In a legal context it refers to a person's ability to do something, including making a decision, which may have legal consequences for themselves or for other people.

When does a person lack capacity?

For the purpose of the MCA, a person lacks capacity if, at the time the decision needs to be made, they are unable to make or communicate the decision because of an 'impairment of, or a disturbance in the functioning of, the mind or brain'. This could be the result of a variety of factors, including mental illness, learning disability, dementia, brain damage, or intoxication. The inability to make the decision, however, *must* be a result of that impairment or disturbance (this is sometimes referred to as the 'causative nexus').

The Supreme Court has confirmed that the correct way to apply the test (which differs to the way it is set out in the MCA code of practice) is as follows:

 Is the person able to make the decision in question at the time it needs to be made?

If they cannot:

2. Is there an impairment or disturbance in the functioning of the person's mind or brain?

If so:

3. Is the person's inability to make the decision *because of* the identified impairment or disturbance?

The assessment of capacity is 'task specific'. It focusses on the specific decision that needs to be made at the specific time the decision is required. It does not matter if the incapacity is temporary, or the person retains the capacity to make other decisions, or if the person's capacity fluctuates.



Basic principles

What are the Act's basic principles?

The MCA sets out several principles that govern decisions made and actions taken under its authority. Where confusion arises about how the Act should be implemented, it can be extremely helpful to refer to them.

Actions or decisions that clearly conflict with these principles are unlikely to be lawful, although there may be occasions where they are in tension, and some balancing will be required. A list of the principles, with brief descriptions, is given below.

A presumption of capacity

It is a fundamental principle of English law that adults have the right to make decisions on their own behalf and are assumed to have the capacity to do so. This means that it is never for an adult to prove their own capacity. Where a person intends to take steps on the basis that the adult lacks capacity to make the relevant decision, that person must be able to explain why they consider that they are allowed to do so, including why the adult can be said to lack capacity.

Maximising decision-making capacity

Closely linked to the presumption of capacity, this principle requires that everything practicable must be done to support an individual to make their own decisions before it is decided that they lack capacity to make the decision(s) in question. For example, advocates and communication support might be necessary, and consideration given to whether an individual's decision-making abilities are affected by the time of day or medication regimes. The aim is to ensure that individuals who can make decisions for themselves but may, nevertheless, need some support, are not inappropriately assessed as lacking capacity — see section 4.6 on supported decision making.

The freedom to make unwise decisions

The fact that an individual makes a rash, unwise or irrational decision, or acts out of character, is not in and of itself proof of incapacity. All adults retain the right to make decisions which seem unwise or irrational to others. Although such actions may raise questions about capacity — where for example they follow a period of illness or an accident — they are not determinative of capacity. What matters is the ability to make the decision, not the content of the decision per se. This means that while an unwise decision might be a reason to consider whether the person has capacity, it cannot be the basis on which they are found to lack capacity.

Best interests

At the heart of the Act lies the principle that where individuals lack capacity, any decision or action taken on their behalf must be in their best interests. Practically speaking, what constitutes an individual's best interests will depend upon the circumstances. Particular attention must be given to statements of current or prior wishes or feelings expressed or made by the individual, and to what is known about the individual's beliefs and values. Further information about best interests can be found in section 4.5. The BMA also has a separate toolkit on best interests decision making for adults who lack capacity (see key resources).



The less-restrictive alternative

Whenever a person is making a decision on behalf of an adult who lacks capacity, they must consider if it is possible to make the decision in a way that is less restrictive of that individual's fundamental rights or freedoms. There are often several ways to achieve a desired outcome, and where possible the choice must be the one that interferes least with the individual's freedoms while still achieving the necessary goal. The option chosen must, however, be in the person's best interests, which may not in fact be the least restrictive.



Key resources

BMA – Best Interests decision-making for adults who lack capacity



Assessing capacity

Who should assess capacity?

The MCA does not specify who should assess capacity when a patient's ability to make a decision has been called into question. However, anyone who wishes to carry out an action in connection with the care or treatment of an individual, or who wishes to make a decision on their behalf, must have a reasonable belief that they lack the requisite capacity. In its guidance on *Decision making and consent* at paragraph 82 the GMC states:

'Assessing capacity is a core clinical skill and doesn't necessarily require specialist input (e.g. by a psychiatrist). You should be able to draw reasonable conclusions about your patient's capacity during your dialogue with them. You should be alert to signs that patients may lack capacity and must give them all reasonable help and support to make a decision.'

If you believe that the patient may lack the capacity to make a specific decision, then you must assess their capacity to make the decision in question, as set out below. Where consent to medical treatment is required, the healthcare professional proposing the treatment is responsible for ensuring that the patient has the capacity to consent before proceeding.

The reasons why capacity is in doubt should be recorded in the medical record, as should details of the assessment process and its findings. The more serious the decision, the more formal the assessment of capacity is likely to be.

If there is doubt about whether the patient lacks capacity to make a specific decision, it can be helpful to seek support from someone who knows the patient well, for example, another member of the healthcare team or someone close to the patient. Although assessing capacity is a core clinical skill, in complex cases, where you remain unclear as to whether the patient has the requisite capacity, you should seek specialist input from colleagues such as psychiatrists or psychologists. You should also seek specialist input if the patient or someone close to them disagrees with your judgement.

How do you assess capacity?

When assessing an individual's capacity to make a specific treatment decision, doctors should ensure, as far as possible, that any factors likely to affect the patient's ability to decide for themselves are addressed beforehand. These may include medication, medical condition, pain, time of day, fatigue, or mood. Any information must be given as clearly and plainly as possible with communication aids used where appropriate. Those assessing a patient's capacity are also under an obligation to enhance their capacity as far as reasonably possible. This will involve seeking to ensure that patients are engaged in decision making when they are best able to participate and are encouraged to participate in decision making to the greatest extent they are able.

The MCA makes use of a 'functional' test of capacity, adapted from the common law, which focusses on the decision-making process itself.

There are three elements to the assessment of capacity:

- 1. an inability to make a decision (the functional test);
- 2. an impairment of, or a disturbance in the functioning of the mind or brain (the impairment/disturbance test); and
- 3. a causal link between the two (in other words, the inability to make a decision must be caused by the impairment).



Under the functional test, a person is regarded as being unable to make a decision if, at the time the decision needs to be made, they are unable, even with all practicable support:

- to understand the information relevant to the decision;
- to retain the information relevant to the decision;
- to use or weigh the information; or
- to communicate the decision (by any means).

Where an individual fails one or more parts of this test, they do not have the relevant capacity. Difficult judgements will still need to be made, particularly where capacity fluctuates; where some capacity is demonstrable but its extent is uncertain; or where the impairment — which does not require a formal diagnosis — may interact with coercion or duress from those close to the individual.

If the impairment which is causing the inability to make a decision is temporary and the decision can reasonably be put off until such time as the individual is likely to regain capacity, then it should be deferred. While it is clear that an unconscious patient will lack capacity, most other patients will retain some decision-making capacity, however slight.

A person should not be assessed as lacking capacity until all reasonable steps have been taken to assist them to make the decision and an assessment that a person lacks the capacity to make a decision must not be discriminatory. It must not be based simply on:

- age;
- appearance;
- assumptions about their condition; or
- any aspect of their behaviour.

In assessing capacity, consideration should be given, where appropriate, to the views of those close to the individual. Family members and close friends may be able to provide valuable background information, although their views about what they might want for the individual must not be allowed to influence the assessment of capacity.

The MCA requires that any decision that a person lacks capacity must be based on a 'reasonable belief' backed by objective reasons. Where there are disputes about whether a person lacks capacity that cannot be resolved using more informal methods, the Court of Protection can be asked for a ruling.

More detailed advice on assessing capacity is available from other sources (see key resources).

What do you do when an individual refuses to be assessed?

Occasionally, an individual whose capacity is in doubt may refuse to be assessed. In most cases, a sensitive explanation of the potential consequences of such a refusal, such as the possibility that any decision they may make will be challenged later, will be sufficient for them to agree. However, if the individual flatly refuses, in most cases no one can be required to undergo an assessment. In these circumstances, doctors should document the refusal in the medical record, make a decision about capacity based on the information they have available, and document the decision reached and the reasons for it; where the question of capacity cannot be resolved on the basis of existing information, legal advice should be sought.



()

If there are reasonable grounds to believe that the refusal of assessment results from coercion by a third party, legal advice should be sought with a view to approaching the courts.

Key resources

BMA and The Law Society – <u>Assessment of Mental Capacity (5th edition)</u>
BMA – <u>Best interests decision making for adults who lack capacity</u>
Capacity Guide – <u>Guidance for clinicians and social care professionals on the assessment of capacity</u>

GMC – <u>Decision making and consent</u>



Best interests

What does the Act mean by best interests?

All decisions taken on behalf of someone who lacks capacity must be taken in their best interests. The Act provides a checklist of common factors that must be considered when making a best interests judgement. Case law has established that when assessing an individual's best interests, decision makers must look at their welfare in the broadest sense. This must extend beyond medical factors to incorporate social and psychological dimensions of wellbeing.

As part of the assessment process the Supreme Court has made clear that the decision maker must make a reasonable effort to put themselves in the place of the patient and ask what their attitude to the proposed treatment would be (see also section 4.6 on supported decision making).

What should you consider when assessing best interests?

Lacking capacity to make a decision should not exclude an individual from participating in the decision-making process as far as possible. The decision maker must also consider whether the person will regain capacity. A decision should be delayed if it can reasonably be left until they regain the capacity to make it.

When determining best interests, assumptions must not be made merely on the basis of the individual's age or appearance, their medical condition, or any aspect of their behaviour — this is the principle of equal consideration and non-discrimination.

In most circumstances it will be clear where the individual's best interests lie, and a decision as to care or treatment will not be challenging or time-consuming — but this is not always the case. Whether to provide analgesics for someone in pain is likely to be a straightforward question; a decision about whether to continue providing life-sustaining treatment is less so. Where a decision is likely to have grave consequences for a person it will require greater consideration, wider consultation with those close to the patient, and more detailed documented evidence about the decision reached and the reasons for it.

Relevant factors to consider are likely to include (so far as they are reasonably ascertainable):

- the person's past and present wishes and feelings, including any relevant written statement made when they had capacity;
- the person's wishes, beliefs, or values where they would have an impact on the decision; and
- other factors the person would have considered if able to do so, such as the effect of the decision on other people.

For significant decisions, a crucial part of best interests assessments involves discussion with those close to the individual, including family, friends, or carers, where it is practical or appropriate to do so, bearing in mind the duty of confidentiality (for more on information sharing, see section 4.18). It should also include anyone previously nominated by the person as someone to be consulted.



Where an individual appointed to act under a Lasting Power of Attorney (see section 4.7) or a deputy appointed to make decisions by the Court of Protection (see section 4.8) has the authority to make the decision, they should be provided with as much information as is necessary for them to make the decision in question.

The BMA has separate guidance on best interests decision making (see key resources).

What about decisions relating to life-sustaining treatment?

Where the decision concerns the provision or withdrawal of life-sustaining treatment (including clinically-assisted nutrition and hydration) the Act makes it clear that the person deciding whether the treatment is in the patient's best interests 'must not be motivated by a desire to bring about the individual's death'.

Are there any exceptions to the best interests principle?

There are two circumstances when the best interests principle will not apply. The first is where someone has previously made an advance decision to refuse medical treatment while they had capacity (see section 4.10). Where the advance decision is valid and applicable, it should be respected, even if others think the decision is not in their best interests. The second exception relates to the enrolment of adults who lack capacity in certain forms of research (see section 4.15).



Key resources

BMA – Best Interests decision making for adults who lack capacity
BMA and Royal College of Physicians – <u>Clinically-assisted nutrition</u>
and hydration (CANH) and adults who lack the capacity to consent.
<u>Guidance for decision making in England and Wales</u>



Supported decision making

What does 'supported decision making' mean?

In 2009, the UK ratified the United Nations Convention on the Rights of People with Disabilities (CRPD). Although not incorporated into UK law, the CRPD has ushered in something of a sea-change regarding the care and treatment of people who may lack capacity to make certain decisions. The focus of the CRPD is on *supported* rather than *substitute* decision making.

The implications of the CRPD are complex and challenging. They may also be in tension with some of the principles of the MCA. In this section we set out ways in which doctors can draw on aspects of the CRPD's supported decision making approach to complement their obligations under the support principle in the MCA (see section 4.3).

Is there a difference between mental and legal capacity under the CRPD?

Yes. Although mental and legal capacity are treated similarly under the MCA, the CRPD relies on a distinction between mental and legal capacity. Legal capacity refers to the formal ability to hold and exercise rights and duties. Under the CRPD, these are universal and cannot be lost. Mental capacity refers to decision-making skills and abilities and these clearly vary from individual to individual.

What does 'supported decision making' mean under the CRPD?

As interpreted by the UN treaty body responsible for the CRPD, the Convention uses the concept of supported decision making in a particular sense. It requires ensuring that people receive the support they need and want to make and express decisions where this is possible. If it is not possible, decisions must be taken in a way that reflects the person's 'will and preferences.' Where their will and preferences are unclear, it is permissible to act according to a 'best interpretation of will and preferences.' This approach now guides decisions made by the Court of Protection. The key difference is that the focus is increasingly on determining what the individual would want — and consider to be in their best interests — in the circumstances, rather than what others believe objectively to be in their best interests.

What measures can enhance supported decision making?

These measures can include:

- exploring with the person how best they can be supported to make decisions;
- identifying, as far as possible, the wishes and feelings of those unable to make decisions. Such wishes and feelings should be complied with when making best interests decisions unless there are compelling reasons to set them aside;
- ensuring facilities are available in healthcare services where assessments
 of capacity are frequent to ensure the proper support of those being
 assessed, including an environment conducive to their maximal
 involvement in decision making; and
- facilitating, as appropriate, the involvement of those close to the individual to support their decision making.

Who is responsible for ensuring appropriate support?

Under the MCA, the obligation to take appropriate steps to support the person to make a decision falls largely on those responsible for assessing the individual's mental capacity. This will include ensuring a conducive environment and ensuring information is provided in an accessible form.



Lasting powers of attorney

What is a Lasting Power of Attorney?

The MCA includes provisions enabling capacitous adults to nominate another individual or individuals to make health and welfare decisions on their behalf when they lack the capacity to make those decisions. This power, known as a Lasting Power of Attorney (LPA), allows the individual (the donor) to give authority to someone else (the attorney) to make decisions on the donor's behalf. The donor decides who the attorney should be and how wide ranging the power should be. More than one attorney can be appointed and they may be appointed to make some decisions jointly (together) and some decisions jointly and severally (independently). If the LPA does not specify this, then the attorneys must act jointly.

Is there more than one type of LPA?

Yes. There are two types of LPA, the property and affairs LPA and the health and welfare LPA. The health and welfare LPA covers personal, welfare, and healthcare decisions, including decisions relating to medical treatment. Although an LPA in relation to property and affairs can be used by the attorney even when the donor still has capacity, an LPA dealing with health and welfare can only operate if the individual lacks capacity in relation to the issue in question.

What effect does a health and welfare LPA have?

The Act allows an individual aged 18 or over who has capacity to appoint an attorney under a health and welfare LPA, to make decisions on their behalf once they lose capacity. For it to be valid it must be in writing — using a specified form — and include:

- information about the nature and extent of the LPA;
- a statement signed by the donor stating that they have read and understood the information and that they want the health and welfare LPA to apply when they lose capacity;
- the names of anyone (other than the attorney(s)) who should be told about an application to register the LPA;
- a statement signed by the attorney(s) stating that they have read the information and understand the duties, in particular the duty to act in the donor's best interests; and
- a certificate completed by a third party, confirming that, in their opinion, the donor understands the nature and purpose of the LPA and that no fraud or pressure has been used to create the LPA.

Registered healthcare professionals can be certificate providers and, GPs in particular, may find they are asked by patients to fulfil this role.

How do you register an LPA?

An LPA must be registered with the Office of the Public Guardian (OPG) before it can be used. It does not give the attorney any legal power to make decisions before it is registered (and a health and welfare attorney can never have any power to act where the donor has capacity to make the decisions in question). The OPG maintains a register of LPAs and, where there is doubt as to the existence of an LPA, anyone can apply to search the register. They also have a fast-track checking mechanism that healthcare staff can use.



What powers does an attorney have under an LPA?

The powers granted to an attorney will depend entirely on the wording of the LPA. If a health and welfare LPA has been registered, the attorney will have no authority to make decisions about the donor's finances or property. Similarly, if a property and affairs LPA has been registered, the attorney will have no power to make any decisions about the medical treatment of the donor. The donor may also have included specific restrictions on the attorney's powers. It is therefore important that healthcare professionals carefully check the wording of the LPA. Even where a health and welfare LPA has been created and no restrictions have been imposed by the donor, an attorney cannot:

- make treatment decisions if the donor has capacity;
- consent to a specific treatment if the donor has made a valid and applicable advance decision to refuse that treatment after the creation of the LPA;
- consent to or refuse life-sustaining treatment unless this is expressly authorised by the LPA;
- consent to or refuse treatment for a mental disorder where a patient is detained under mental health legislation; or
- demand specific treatment that healthcare professionals consider is not necessary or appropriate for the donor's particular condition.

Where an attorney is acting under a health and welfare LPA and they are making decisions in relation to medical treatment, they must act in the donor's best interests. This means healthcare professionals need, independently, to have their own view as to what is in the best interests of the donor so that they can engage with the attorney on an informed basis. If any doubt or disagreement about what is in the donor's best interests cannot be resolved locally, an application can be made to the Court of Protection.

There may be occasions when an attorney cannot face making particularly serious decisions, such as regarding life-sustaining treatment. In these circumstances, those responsible for providing care and treatment should revert to the best interests decision-making process set out in section 4.5.

What are the differences between an Enduring Power of Attorney and an LPA?

There is a common misunderstanding among patients and their families (and indeed among some healthcare professionals) that an attorney acting under an Enduring Power of Attorney (EPA) has the same power as an attorney acting under a health and welfare LPA. They do not, and it is frequently necessary for a sensitive conversation to take place to explain that an attorney under an EPA does not have any specific decision-making role in relation to health and welfare decisions.

The fundamental difference between the two is that EPAs cover decisions relating to property and financial affairs only, whereas there are two types of LPA, one to deal with financial affairs and one to deal with personal welfare and medical treatment decisions. Although no new EPAs can be made, any that were made before 1 October 2007, and are registered, remain legally effective. LPAs will eventually replace the existing system of EPA, but there will be a number of years during which the two systems continue to co-exist.



Key resources

Office of the Public Guardian





Court of Protection and Court-appointed deputies

What is the function of the Court of Protection?

The Court of Protection was established by the MCA to oversee the proper functioning of the legislation. The Court has the power to rule on the validity of LPAs as well as to determine their meaning or effect. It also has the power to make a declaration as to whether an individual has or lacks capacity to make particular decisions, and to rule on cases where there is doubt or dispute as to whether a particular treatment is in the best interests of an adult who lacks capacity. The Court of Protection is also likely to need to approve some specific types of treatment or procedures where additional safeguards are considered necessary (see section 4.12).

What are Court-appointed deputies?

The Court of Protection can appoint deputies as substitute decision makers where a person either never had, or loses, capacity to make relevant decisions and has not appointed an attorney under an LPA.

Deputies can be appointed to make decisions on health and welfare as well as financial matters. They are likely to be appointed where an ongoing series of decisions is needed to resolve an issue, rather than a single decision of the Court

In most cases, the deputy is likely to be a family member or someone who knows the patient well. However, the Court may sometimes appoint a deputy who is independent of the family, if, for example, there is a history of serious family dispute or the individual's health and care needs are complex.

As with attorneys appointed under an LPA, deputies must make decisions in the individual's best interests and must allow the individual to make any decisions for which they have capacity. Deputies cannot refuse lifesustaining treatment.

Deputies should inform the healthcare professional with whom they are dealing that the Court has appointed them as a deputy. Deputies will have been provided with official documentation in relation to their appointment. Healthcare professionals should review the documentation to confirm the extent and scope of the authority given by the Court. Healthcare professionals will need, independently, to have their own view as to what is in the best interests of the individual so that they can engage with the deputy on an informed basis. If any doubt or disagreement about what is in the individual's best interests cannot be resolved locally, an application can be made to the Court of Protection.

What are Court of Protection section 49 reports and what obligations do they entail?

Under section 49 of the MCA, the Court of Protection can order reports from NHS health bodies and local authorities when it is considering any question relating to someone who may lack capacity and the report must deal with 'such matters as the Court may direct.' An order under section 49 of the MCA places an obligation on the NHS body to comply, although it is for the NHS body to determine the appropriate person to complete the report. There is no right to charge a fee for preparing a section 49 report. The BMA has separate guidance on section 49 reports (see key resources).



Key resources

BMA – Section 49 guidance



Independent Mental Capacity Advocates

What is an Independent Mental Capacity Advocate (IMCA)?

IMCAs support and represent particularly vulnerable adults who lack capacity to make certain decisions where there are no family members or friends available or willing to be consulted about those decisions. An IMCA is independent of the healthcare professional making the decision and represents the patient in discussions about whether the proposed decision is in the patient's best interests. An IMCA does not have the authority to make decisions, but can raise questions or challenge decisions which appear not to be in the patient's best interests.

When should an IMCA be instructed?

An IMCA must be instructed in relation to individuals who lack capacity and who have no family or friends whom it is appropriate to consult when:

- an NHS body is proposing to provide, withhold or stop 'serious medical treatment'; or
- an NHS body or local authority is proposing to arrange accommodation (or a change in accommodation) in a hospital or care home, and the stay in hospital will be more than 28 days, or the stay in the care home more than 8 weeks.

Whilst it is not compulsory, IMCAs may also be instructed in a case review of arrangements for accommodation.

There is no discretionary power to appoint IMCAs in other circumstances. This means there is no power to appoint an IMCA where decisions are being made outside a hospital setting or where a non-NHS body is responsible for the care being provided. Nevertheless, where an adult who lacks capacity has no family members or friends available or willing to be consulted, healthcare professionals should take particular care to identify all relevant evidence about what the patient would wish.

An IMCA cannot be instructed if an individual has previously named a person who should be consulted about decisions that affect them, and that person is willing to assist, or they have appointed an attorney under a health and welfare LPA or the Court of Protection has appointed a welfare deputy to act on the patient's behalf. There is also no duty to instruct an IMCA where there is a need to make an urgent decision, for example, to save a patient's life. If a patient requires treatment whilst a report is awaited from an IMCA, this can be provided in the patient's best interests. It is also not necessary to instruct an IMCA for patients detained under mental health legislation.

Responsibility for instructing an IMCA lies with the NHS body or local authority providing the treatment or accommodation.



What is 'serious medical treatment'?

Serious medical treatment is defined as treatment which involves providing, withdrawing, or withholding treatment where:

- in the case of a single treatment being proposed, there is a fine balance between its benefits to the patient and the burdens and risks it is likely to entail:
- in the case where there is a choice of treatments, a decision as to which one to use is finely balanced; or
- what is proposed would be likely to involve serious consequences for the patient.

Examples of serious medical treatment might include chemotherapy and surgery for cancer, therapeutic sterilisation, major surgery, withholding or stopping clinically-assisted nutrition and hydration, and termination of pregnancy.

What are the powers of an IMCA?

To provide necessary support to an adult who lacks capacity an IMCA will have powers to:

- examine health records which are relevant and necessary to deal with the issue:
- consult other persons who may be able to comment on the individual's wishes, feelings, and beliefs;
- ascertain what alternative courses, actions, and options may be available to the individual; and
- obtain an alternative medical opinion.

An IMCA is required to write a report to the NHS body or local authority responsible for the individual's treatment or care. The IMCA's report must be considered before the final decision is made.



Key resources

Office of the Public Guardian and Department of Health and Social Care – <u>Making Decisions – The Independent Mental Capacity Advocates Service</u>

 $Social\ Care\ Institute\ for\ Excellence-\underline{Independent\ Mental\ Capacity}$ $\underline{Advocates}$



Advance decisions to refuse treatment

Are advance decisions to refuse treatment legally binding?

The MCA makes clear that somebody who is aged 18 or over and has the necessary mental capacity can refuse specified medical treatment for a time in the future when they may lose the capacity to make the decision. This is known as an advance decision to refuse treatment (ADRT).

The MCA's powers are restricted explicitly to advance decisions to refuse treatment. An advance refusal of treatment is binding if:

- the person making the decision was 18 or older when it was made, and had the necessary mental capacity;
- it specifies, in lay terms if necessary, the specific treatment to be refused and the particular circumstances in which the refusal is to apply;
- the person making the decision has not withdrawn the decision at a time when they had the capacity to do so;
- the person making the decision has not appointed, after the decision was made, an attorney to make the specified decision; and
- the person making the decision has not done anything clearly inconsistent with the decision remaining a fixed decision.

When assessing the validity of an ADRT, it is important to remember the principle of the presumption of capacity. The MCA code of practice makes clear that healthcare professionals should always start from the presumption that a person who has made an advance decision had capacity to make it, unless there are reasonable grounds to doubt the person had the capacity to make the advance decision at the time they made it. In cases of genuine doubt about the existence or validity of an advance decision, doctors can provide treatment that is immediately necessary to stabilise or to prevent a deterioration in the patient's condition until the existence, and the validity and applicability, of the advance decision can be established. If doubts cannot be resolved locally, and time permits, legal advice should be sought about applying to the Court of Protection for a declaration.

Advance requests for future treatment, or statements about matters other than medical treatment, are not legally binding, although they can be a very useful indication of a patient's wishes and feelings when making best interests decisions

Are there limits to advance decisions to refuse treatment?

Although any written or oral statements of patients' future wishes are clearly a vital part of decision making, there are limits to patients' ability to influence their future care. Nobody can authorise or refuse in advance procedures they could not authorise or refuse contemporaneously. They cannot, for example, insist upon treatment that is not clinically indicated. In the BMA's view, it would also be inappropriate for patients to refuse in advance the provision of all forms of 'basic care' such as hygiene and interventions designed solely for the alleviation of pain or distress. This also includes the offer of oral food and water (but not clinically-assisted nutrition and hydration). An advance decision to refuse treatment cannot be used to give effect to an unlawful act.



Do advance decisions apply to individuals subject to compulsory mental health legislation?

Where a patient is subject to compulsory treatment under mental health legislation, an advance refusal relating to treatment provided for the mental disorder for which compulsory powers have been invoked will not be binding, except in respect of treatment delivered in the community under a Community Treatment Order and in some cases of electro-convulsive treatment (ECT). The courts have, however, established that the treating team should proceed with caution before overriding an advance decision made to refuse medical treatment for mental disorder. This could include, for example, considering whether there are any other treatment options available that are less restrictive. An agreed advance treatment plan for mental health conditions can be helpful and would represent a kind of advance statement, although it would not be binding during periods of compulsion.

Is there a specific format for advance decisions to refuse treatment?

Apart from decisions relating to life-sustaining treatment, discussed below, the MCA does not impose any formal requirements for ADRTs. Both written and oral decisions can be valid, provided they are supported by sufficient evidence of their validity and applicability. It is worth bearing in mind that advance decisions can also be recorded, for example on smart phones, although patients have to take appropriate steps to ensure relevant people are made aware of their existence.

The MCA Code of Practice recommends that any ADRT includes the following:

- full details of the person making the advance decision, including date of birth, home address, and any distinguishing features;
- the name and address of the person's GP and whether they have a copy of the document;
- a statement that the ADRT should be used if the person ever lacks capacity to make treatment decisions;
- a clear statement of the decision, the treatment to be refused, and the circumstances in which the decision will apply;
- the date the document was written (or reviewed);
- the person's signature (or the signature of someone the person has asked to sign on their behalf and in their presence); and
- the signature of the person witnessing the signature, if there is one (or a statement directing somebody to sign on the person's behalf).

Where an advance decision is made verbally, healthcare professionals should make a record in the patient's notes, which should include:

- a note that the decision should apply if the person lacks capacity to make treatment decisions in the future;
- a clear note of the decision, the treatment to be refused, and the circumstances in which the decision will apply;
- details of someone who was present when the oral advance decision was recorded and the role in which they were present (for example, healthcare professional or family member); and
- whether they heard the decision, took part in it, or are just aware that it exists.

Although not a legal requirement, it is recommended that ADRTs are reviewed regularly, particularly where there are any material changes in the individual's condition or treatment options, and at least every five years.



Can advance decisions extend to refusing life-sustaining treatment?

Although advance decisions can be oral or in writing, an advance refusal will only apply to life-sustaining treatment where it is in writing, is signed and witnessed, and contains a statement that it is to apply even where life is at risk.

How should advance decisions be stored?

The storage of advance decisions, and the obligation to ensure that relevant healthcare professionals are aware of them, are the responsibility of those who make them. A copy of any written ADRT should be given to the patient's GP for storage in the medical record. A copy of the document should be provided to another healthcare professional involved in the patient's care on request. Where possible, the patient should draw it to the attention of hospital staff before an episode of care. It is good practice for anyone who makes an ADRT to draw it to the attention of anyone who may be called upon to assist in making decisions on their behalf, such as friends, family, or any welfare attorney.



Treatment in an emergency

Can emergency treatment be provided to adults who lack the capacity to consent?

In an emergency, where consent cannot be obtained, doctors should provide treatment that is immediately necessary either to preserve life or to prevent a serious deterioration in the patient's condition. The only exception to this is where there is clear evidence of a valid and applicable advance decision to refuse the treatment in question (see section 4.10). Emergency treatment does not have to be restricted to what is immediately necessary. Applying the principles set out above, to consider the person's capacity and best interests, it can also include steps to prevent deterioration in order to ensure that recovery is an option. Where decisions can reasonably be delayed until such time as the adult is likely to regain capacity, or to permit an assessment of capacity and discussion with those close to the patient, then they should be.

What should you do if, in an emergency, a patient refuses treatment and there is doubt about their capacity?

Doctors should take whatever steps are necessary to prevent deterioration in the patient's condition, and then consider questions of capacity and consent. These steps should also be taken if a welfare attorney, with the relevant authority, refuses to give consent but the doctor in charge judges that treatment would be in the best interests of the patient. Once essential treatment has been given, the procedures for resolving disagreement between doctors and attorneys must be followed (see section 4.17). Where it is clear that a patient has capacity to refuse treatment, or has a valid and applicable advance decision to refuse treatment, doctors cannot provide the treatment unless authorised under mental health legislation. For more information on advance decisions to refuse treatment, see section 4.10.



Treatment requiring special safeguards

What treatments require special safeguards?

For most day-to-day healthcare decisions, the procedures and principles outlined in this guidance are sufficient. There are some treatments, however, that are generally regarded as being more serious or controversial and require either special safeguards, or in the case of the most complex and difficult decisions, referral to court.

What treatments require an application to the court?

Case law and Court of Protection guidance have made clear that certain categories of cases are ones where legal advice should be sought to determine whether an application to court is required. These are cases where:

- at the end of the decision-making process:
 - the decision is finely balanced;
 - there is a difference of medical opinion;
 - there is a doubt or dispute that cannot be resolved locally (see section 4.17) about whether a particular treatment will be in a person's best interests; or
 - there is a conflict of interest on the part of those involved in the decision-making process that cannot be appropriately managed;
- a medical procedure or treatment is for the primary purpose of sterilisation;
- the procedure is for the purpose of donation of an organ, bone marrow, stem cells, tissue, or bodily fluid to another person;
- the action proposed involves a procedure for the covert insertion of a contraceptive device or other means of contraception;
- it is proposed that an experimental or innovative treatment be carried out;
- the case involves a significant ethical question in an untested or controversial area of medicine.

An application to court may be required where the proposed procedure or treatment will require a degree of force to restrain the person concerned and the use of restraint constitutes a deprivation of liberty (see section 4.14). It is also advisable to seek legal advice where the proposed action involves the use of deception to deliver medical treatment (such as covert medication) to the patient on a regular or long-term basis.



Is Court approval required for decisions relating to the proposed withholding or withdrawal of clinically-assisted nutrition and hydration (CANH) from patients in a persistent vegetative state or a minimally conscious state?

Case law and Court of Protection guidance have made clear that there is no legal obligation to seek Court approval for these decisions unless, at the end of the best interests assessment:

- the way forward is finely balanced;

British Medical Association

- there is a difference of medical opinion;
- there is a lack of agreement to a proposed course of action from those with an interest in the patient's welfare; or
- there is a potential conflict of interest on the part of those involved in the decision-making process which cannot be appropriately managed.

Doctors making decisions about CANH for adults who lack capacity should follow the joint BMA and Royal College of Physicians' (RCP) guidance (see key resources).



Key resources

Applications relating to medical treatment; guidance authorised by the Honourable Mr Justice Hayden, the Vice-President of the Court of Protection

BMA and RCP — <u>Clinically-assisted nutrition and hydration (CANH) and</u> <u>adults who lack the capacity to consent. Guidance for decision-making in England and Wales</u>



Restraint and restrictive measures

What is restraint?

There may be occasions when healthcare professionals need to consider the use of restraint in treating an individual lacking capacity. The MCA states that restraint is the use or threat of force, to make someone do something they are resisting, or restricting a person's freedom of movement, whether they are resisting or not. The MCA only refers to restraint to prevent harm to the patient. Healthcare professionals have a common law right to use proportionate restraint to prevent the immediate risk of harm to others.

What are the types of restraint?

Restraint can be overt, such as the use of bed rails. It can also be covert and indirect such as having doors that are heavy and difficult to open or putting patients in low chairs from which they find it difficult to move. Restraint may be:

- physical holding by one or more persons;
- mechanical the use of equipment such as bed rails or mittens to stop patients removing nasogastric tubes or catheters;
- chemical involving medication, for example sedation; or
- psychological telling patients that they are not allowed to do something or taking away aids necessary for them to do what they want, for example spectacles or walking aids.

When is restraint lawful?

Restrictive measures should be a last resort and alternatives to restraint must always be considered. Anybody proposing to use restraint must have objective reasons to justify that it is necessary. They must also be able to show that the patient is likely to suffer harm unless proportionate restraint is used. A proportionate response means using the least intrusive type and the minimum amount of restraint for the smallest amount of time to achieve the objective, in the best interests of the patient lacking capacity. The use of restraint must also be proportionate to the likelihood and seriousness of harm.

If these conditions are met, it is permissible to restrain a patient to provide necessary treatment. It also follows that in such circumstances there would be no liability for assault. The restraint must not amount to a deprivation of liberty and if it is considered necessary to deprive someone of their liberty to protect their interests, special safeguards must be employed. For further information on deprivation of liberty, see section 4.14.

Restraint is less likely to be required where the MCA principles are followed and there is a genuine understanding of the person's wishes, feelings, beliefs and values.

Further information about the use of restraint can be found in the MCA Code of Practice (see key resources)



Key resources

Department for Constitutional Affairs – <u>Mental Capacity Act 2005 – Code of Practice</u>



Care and treatment amounting to deprivation of liberty – the Deprivation of Liberty Safeguards regime (DoLS)

What is the legal basis for a deprivation of liberty for adults?

The MCA makes clear that people who lack the ability to consent to treatment should be cared for in accordance with the 'less restrictive principle' – see section 4.3. As outlined in section 4.13, there will be times when this might involve imposing restrictions on a person's liberty. There will be circumstances however in which appropriate and necessary care or treatment that is in an individual's best interests can only be provided in circumstances that will amount to a 'deprivation of liberty.'

Any such deprivation of liberty will only be lawful if it is authorised, either in accordance with procedures set out in the Deprivation of Liberty Safeguards (DoLS) which were added to the Mental Capacity Act by amendments introduced by the Mental Health Act (MHA) 2007, or by a court order. This section gives a brief outline of relevant factors to consider when assessing whether an individual is, or might be, deprived of liberty and outlines the procedure for seeking authorisation. Although individuals may be deprived of their liberty in a variety of settings, including domestic ones, this section focusses on deprivation of liberty in hospitals and care homes where DoLS apply. If a person is to be deprived of their liberty in another setting, a court order will be required.

This is a complex area of law and practice and where doctors identify individuals who may be, or who may need to be, deprived of their liberty they should refer to local protocols, and/or take legal advice.

What are the key points for healthcare professionals?

The key points are as follows:

- the fact that care or treatment amounts to a deprivation of liberty does not mean that it is inappropriate. It means only that it reaches a certain threshold of restriction such that authorisation is required;
- identifying and authorising a deprivation of liberty should not be a substitute for or impede the delivery of the highest standard of care;
- the focus of decision making must remain the best interests of the patient;
- nothing in the MCA or DoLS is designed to prevent the provision of timely and appropriate medical treatment. In an emergency, treatment must not be delayed for the purpose of identifying whether a deprivation of liberty has taken place or seeking its subsequent authorisation; and
- an authorisation for a deprivation of liberty does not provide legal authority for treatment. Treatment for adults unable to consent must be given on the basis of an assessment of their best interests or in accordance with another legal provision of the MCA.



When might it be appropriate to deprive a patient of their liberty?

Depriving a patient of liberty may be justifiable if:

- it is in their best interests to protect them from harm;
- it is a proportionate response when compared with the harm faced by the person; and
- there is no less-restrictive alternative.

What are the three components of a deprivation of liberty?

The courts have established that there are three parts to a deprivation of liberty:

- the person is being confined in a restricted space for a non-negligible period (the objective element);
- the person has not validly consented to that confinement (the subjective element); and
- the state is responsible for the confinement (state imputability).

What constitutes a deprivation of liberty?

The concept of 'deprivation of liberty' is not straightforward. The Act does not provide a definition of 'deprivation of liberty', referring instead to the meaning of Article 5 of the European Convention on Human Rights.

The Supreme Court judgment in <u>Cheshire West</u> in 2014 introduced an 'acid test' for what constitutes a deprivation of liberty for the purposes of Article 5. When considering whether an individual may be deprived of their liberty, healthcare professionals should ask three key questions:

- is the person subject to 'continuous supervision and control'?
- is the person 'free to leave'?
- does the person lack the capacity to consent to their care and treatment in those circumstances?

If the person is under continuous supervision and control (sometimes also identified as 'complete supervision and control') and is not free to leave and lacks the capacity to consent to their care and treatment in those circumstances, then the acid test is met. The individual is therefore deemed to be deprived of liberty under Article 5 and authorisation for the deprivation must be sought.

Following the 2017 case of *R* (*Ferreira*) *v Inner South London Senior Coroner* it has been established that where a patient is being treated for a serious physical condition, is unable to give consent to any consequent loss of liberty, and a loss of liberty arises from the patient's condition, not from any imposed constraints, then that individual will not be deprived of liberty under Article 5 of the European Convention on Human Rights (ECHR), so long as the loss of liberty is due to the need to provide care for them on an urgent basis because of their serious medical condition, is necessary and unavoidable, and results from circumstances beyond the state's control. It follows therefore that no authorisation will be required.

In other words, the starting point is that there is no deprivation of liberty, even if the patient cannot consent to the arrangements, where:

- the patient is so unwell that they are at immediate risk of dying anywhere other than in hospital; and
- the arrangements for delivering treatment to the patient are the same as they would be if the patient were able to agree to them.



What are continuous (or complete) supervision and control?

When considering whether an individual is subject to 'continuous or complete supervision and control', it can be helpful to ask whether there is a care plan in place that means that those looking after the individual will be aware at any time:

- where the individual is;
- what the individual will be doing; and
- what steps they will take if they cannot establish the above.

What is a non-negligible period of time?

Case law has also established that, for the purposes of Article 5, any deprivation of liberty must be for a 'non-negligible' period of time. There is no definition of a 'non-negligible' period of time, but in general the more intense the measures of restraint and the greater the resistance or resentment of the individual, the shorter will be the period. The courts have regarded as little as forty minutes of intense restraint as amounting to a deprivation of liberty.

In deciding whether a confinement for a short period of time will amount to a deprivation of liberty, the following factors should be considered. The presence of any of these will make it more likely that a deprivation of liberty will be, or is, occurring:

- the use or threat of force or coercion;
- particularly severe or serious forms of restraint; and
- the consequences of the restrictions for the person.

When is someone free to leave?

Whether a person is 'free to leave' will depend on whether they are free to come and go or to decide to live elsewhere or whether they would require permission. If permission is required, it is likely that they are not free to leave and therefore this part of the deprivation of liberty test has been satisfied.

Does the person have capacity to consent to that deprivation of liberty?

In addressing this question, the attention must be on the specific circumstances of the individual's care and treatment. The question must be: does the individual have the capacity to consent to the specified care and treatment in the concrete circumstances that are proposed or in place?

What factors are not relevant to a deprivation of liberty?

The purposes for which care and treatment are being provided are not relevant to whether a person is being deprived of their liberty, nor are the nature of any disabilities they may have. Similarly, a person's compliance or lack of objection are not relevant, nor is the agreement of family or carers, the appropriateness or 'normality' of the treatment or the lack of an alternative safe place for treatment.

How do you authorise a deprivation of liberty?

Where it is identified that an individual may be deprived of liberty in a care home or hospital and lacks the capacity to consent, that deprivation of liberty must be authorised under the Deprivation of Liberty Safeguards (DoLS). To do this the 'managing authority' of the hospital or care home must apply to a 'supervisory body' — usually the local authority where the person lives. There are two types of DoLS authorisation: standard and urgent.



Standard authorisations

After receiving an application for a standard authorisation, the supervisory body must decide within 21 days whether the person can be deprived of their liberty. If the conditions are met, the supervisory body must authorise the deprivation of liberty and inform the person and managing authority in writing. It can be authorised for up to one year. The person does not have to be deprived of liberty for the period of authorisation. The restrictions should stop as soon as they are no longer necessary.

Urgent authorisations

There will be times when a person may need to be deprived of their liberty before a standard authorisation can be provided. In these situations, the managing authority can itself issue an urgent authorisation which can last up to seven days, with an option to extend it for a further seven days if the supervisory body agrees. When issuing an urgent authorisation, the managing authority must also request a standard authorisation.



Key resources

Department of Health and Social Care – <u>Notes on deprivation of liberty</u>
<u>Supreme Court judgments</u>

Faculty of Intensive Care Medicine – <u>MIDNIGHT LAW: Deprivation of</u> Liberty In Intensive Care

The Law Society – <u>Deprivation of Liberty Safeguards: A practical guide</u> (commissioned by the Department of Health and Social Care)



Research

Can patients who lack capacity participate in research?

Yes. Under the MCA it is lawful to involve adults who lack capacity in research provided it is related to the condition, or treatment for the condition, from which they are suffering. Research must be approved by an appropriately established research ethics committee, or, in Wales, its equivalent. It must not be possible to conduct the research with individuals who have the capacity to consent. (Different rules apply to participation in clinical trials — see below.)

Where the research is 'therapeutic' and is expected to benefit the individual directly, the risks must not be excessive in relation to the anticipated benefits. Where the research is not expected to deliver direct benefit to the patients but is intended to investigate the condition from which they suffer, the risk to individuals must be negligible and any restriction or intrusion must be kept to a minimum.

Clinical trials under Medicines for Human Use (Clinical Trials) Regulations 2004 are subject to their own rules and regulations and guidance should be sought from professional bodies and health and social care guidance before such trials are carried out. (In April 2014, the EU adopted the Clinical Trials Regulations 2014 to repeal the earlier Directive on which the 2004 Regulations are based. However, it had not become applicable in the EU when the UK exited the EU and will therefore only be incorporated into UK law if specific, domestic steps are taken to bring this about.)

What safeguards exist for individuals who lack capacity?

Before an adult who lacks capacity can be involved in research, the researcher must make reasonable efforts to identify someone who is close to them — although not in a professional capacity — who is willing to be consulted about the appropriateness of their involvement. This will ordinarily be a family member. It could also be a welfare attorney or court-appointed deputy.

The following additional safeguards are provided under the Act once the research has started:

- nothing should be done to adults who lack capacity as part of the research to which they appear to object, unless it is intended to protect them from harm or to reduce or prevent pain or discomfort;
- where individuals who lack capacity show signs of distress or resistance, or indicate by any means the wish not to continue in the research, they must be withdrawn;
- the interests of individuals must outweigh the interests of medical science and society; and
- nothing must be done that is contrary to any advance decision or statement, or prior statement of wishes or preferences – provided those statements or decisions have not subsequently been withdrawn.

Where an adult is withdrawn from research, they may continue to receive any treatment they had received as part of the research where there are good grounds to believe that its withdrawal would pose a significant risk to the individual's health.



Can research take place in an emergency where the patient lacks capacity?

In December 2006, an amendment to the 2004 Clinical Trials Regulations introduced provisions enabling patients to be enrolled in clinical trials of pharmaceutical products without prior consent in emergency situations where the research is approved by an appropriate research ethics committee. Where research falls outside the Clinical Trials Regulations it would need to be lawful under the terms of the MCA.

Given the potential vulnerability of adults lacking capacity who are enrolled in research, it is important that doctors undertaking such research are familiar with the substantial body of guidance reflecting international standards for research involving patients who lack capacity.

Is there research that does not require the safeguards in the MCA?

Some research does not require the consent of the person subject to the research and can therefore be done without consent and without the safeguards in the MCA. This includes:

- some research including anonymised data (such as statistics);
- research using confidential patient information under the Health Service (Control of Patient Information) Regulations 2002; and
- research with anonymised human tissues under the Human Tissue Act 2004.

Can doctors provide innovative treatment to patients lacking the capacity to consent to it?

Doctors have always modified methods of investigation and treatment in light of experience and so innovative therapy is a standard feature of good care. There are occasions however where innovative treatment may involve exposing patients to significant risk. Where adults lack the capacity to consent to innovative treatment, any such treatment must be governed by the MCA, in particular it must be in the person's best interests. Where any proposed treatment differs significantly from existing practice and involves unknown or significant risk, considerable care must be taken as innovation can give rise to legal and ethical uncertainty. In these circumstances, it is advisable to seek both expert clinical scrutiny and legal advice.



Relationship with the Mental Health Act

MHA or MCA?

The relationship between the Mental Capacity Act (MCA) and the Mental Health Act (MHA) is a key issue for healthcare professionals. Historically, mental health and mental capacity legislation have had different aims, with the focus of mental health legislation being on managing risk, while capacity legislation has focussed on supportive decision making. In some circumstances healthcare professionals can be uncertain as to which legal framework to use.

The MHA code of practice (see key resources) contains detailed practical guidance on decisions about whether to use the MCA or the MHA.

Where an individual lacks capacity to consent to treatment for mental disorder, and it is reasonable and possible to do so, professionals should generally apply the provisions of MCA, since it is likely to be less restrictive of a person's human rights and freedom of action. However, there may be circumstances when the more formal safeguards provided under mental health legislation, may be more appropriate, including, for example, where:

- it is not possible to give the person the care or treatment they require without doing something that will deprive them of their liberty;
- the person needs treatment that cannot be given under the MCA, such as where the person has made a valid and applicable advance decision to refuse the proposed treatment or part of it;
- the person may need to be restrained in a way that is not permitted under the MCA;
- it is not possible to assess or treat the person safely or effectively without using compulsory powers; or
- the person may lack capacity in some areas but retains the capacity to refuse a vital part of the treatment and has done so.

What is the MCA/MHA interface?

There may be circumstances in which either legal framework may apply and the question as to which Act applies will be for the judgement of the healthcare professional. However, as a rule of thumb if the patient retains capacity the MCA cannot be used. If the treatment is for a physical condition, then the MHA cannot be used. Where detention is deemed necessary, the MHA should be used provided the relevant grounds are met.

Where a patient who lacks capacity has a physical disorder that arises as a 'consequence' of their mental disorder, it is possible that treatment can be provided under either mental capacity or mental health legislation. In relation to the choice as to which legislative framework to use in these circumstances, the BMA recommends that where there is resistance or objection to treatment, either for a mental disorder or for a physical disorder that is a consequence of the mental disorder, mental health legislation should be used. In the absence of resistance or objection from the patient, mental capacity legislation can be used, provided the patient meets the relevant criteria.



Except in respect of treatment delivered in the community under a Community Treatment Order and some cases of electro-convulsive therapy (ECT), advance decisions relating to compulsory treatment provided under the authority of the MHA are not binding — although the courts have established that the treating team should proceed with caution before overriding such a decision. Where, however, a valid and applicable advance decision exists for treatment not covered by the compulsory powers of the MHA, it is likely to be binding. Similarly, where an adult is subject to compulsory powers, all non-MHA decisions relating to their general care and treatment — for which they lack capacity to consent — will be covered by the MCA.



Key resources

Department of Health – Code of Practice: Mental Health Act 1983



Dispute resolution

When can disputes occur?

There may be occasions in relation to the care and treatment of a person who may lack capacity where disagreements arise. These may relate to:

- whether an individual retains the capacity to make a decision;
- whether a proposed decision or intervention is in the person's best interests; or
- whether the decision or the intervention is the most suitable of the available options.

It is clearly in everybody's interests that disagreements are resolved as soon as possible, and with as much consensus as possible. Broadly speaking, disputes can be resolved either informally or formally. Some disputes will be so serious that it may be necessary to make an application to the Court of Protection. This section sets out briefly the different options available for resolving disputes in relation to adults who lack capacity.

How should a dispute be approached initially?

Many disputes can either be avoided, or settled rapidly, by using good communication and involving all relevant individuals. Where healthcare professionals are involved in a dispute with those close to an adult who lacks capacity, it is a good idea to:

- set out the different options in a way that can be clearly understood;
- invite a colleague to talk the matter over and offer a second opinion;
- consider enrolling the services of an advocate; and
- arrange a meeting to discuss the matter in detail.

When should mediation be considered?

Where the methods outlined above do not successfully resolve the dispute, it may be a good idea to involve a mediator. Any dispute that is likely to be settled by negotiation is probably suitable for mediation. A mediator is an independent facilitator. It is not the role of a mediator to make decisions or to impose solutions. The mediator will seek to facilitate a decision that is acceptable to all parties in the dispute.

What if a complaint is made?

It may be that as part of the dispute resolution process, those acting on behalf of an adult who lacks capacity might wish to lodge a complaint about the services they have received. Healthcare professionals should be able to provide information about which complaint procedures would be appropriate in the circumstances. Initially the Patient Advice and Liaison Service (PALS) may be able to deal with the problem informally. PALS does not investigate complaints, but it can, where appropriate, direct people to the formal NHS complaints process.

What role does the Court of Protection have in disputes?

The Court of Protection is the final arbiter in relation to matters arising under the Act. Where disputes have arisen that cannot be resolved in any other way, legal advice should be sought and it may be necessary to make an application to the Court of Protection. Where this is the case, relatives and carers of the patient, and where possible, the patient, should be informed and advised to seek legal representation.



Going to court can be distressing for those concerned. However, the benefits are that a court can give rulings very quickly when necessary, and it can provide a protective role for both patients and the healthcare team who treat them in cases where there is a disagreement that cannot be resolved.



Key resources

Apply for a one-off decision from the Court of Protection



Confidentiality and information sharing

Do healthcare professionals owe a duty of confidentiality to patients who lack capacity?

Yes. Healthcare professionals owe the same duty of confidentiality to all their patients whether or not they lack capacity. Healthcare professionals may therefore usually only disclose information about an adult who lacks capacity where it is in the patient's best interests.

What are the roles of proxy decision makers and IMCAs?

Welfare attorneys and court appointed deputies whose authority extends to medical decisions have the right to give or withhold consent to treatment and so must be involved in treatment decisions, although where emergency treatment is required, this may not always be possible or practicable (see section 4.11).

Where a patient lacks capacity and has no relatives or friends who can be consulted, the Act requires an Independent Mental Capacity Advocate (IMCA) to be appointed and consulted about all decisions about 'serious medical treatment', or place of residence – see section 4.9. The healthcare team must provide the attorney, deputy, or IMCA with all relevant information including the risks, benefits, side effects, likelihood of success, and level of anticipated improvement if treatment is to be given, the likely outcome if treatment is withheld and any alternatives that might be considered. While it will therefore be necessary for attorneys, deputies, and IMCAs to have information that will enable them to act or make decisions on behalf of the patient, it does not mean that they will always need to have access to all the patient's records. Only information relevant to the issue in question should be disclosed.

What role do relatives, carers, and friends have?

Where patients lack mental capacity to consent to disclosure it is usually reasonable to assume that they would want people close to them to be given information about their illness, prognosis, and treatment unless there is evidence to the contrary. This does not however mean that all information should be routinely shared. Where the information is particularly 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.

Those close to a patient who lacks capacity have an important role in decision making whether they have a formal role as a proxy decision maker (attorney or deputy), or more informally in terms of helping the healthcare team to assess the patient's best interests. It may not be possible to carry out these roles without some information being provided about the medical condition of the patient.

Is there a role for 'next of kin'?

Despite the widespread use of the phrase 'next of kin' this is neither defined, nor does it have formal legal status in relation to decision making about medical treatment. A 'next of kin' has no rights of access to a patient's medical records or to information on a patient's medical condition. On the other hand, if, prior to losing capacity, a patient nominates a 'next of kin' and gives authority to discuss their condition with them, they can provide valuable information to the staff looking after the patient.



There are no rules about who can and cannot be a next of kin. A patient may nominate their spouse, partner, member of their family, or friend. A patient's family cannot argue who should be the next of kin if the patient has not made a nomination as there is no legal status attached to it.

It is important not to confuse the concept of next of kin with the role of 'nearest relative' under the Mental Health Act (MHA). The individual authorised to undertake that role is subject to the statutory rules under the MHA which are wholly distinct from any nomination of next of kin.

What rights of access does the Office of the Public Guardian have?

The MCA gives the Public Guardian a right of access to the health records of patients who lack capacity. The Office of the Public Guardian (OPG), or a Court of Protection visitor acting on the instructions of the OPG, may therefore ask a healthcare professional to see a patient's records while it is investigating the actions of a deputy or attorney. For example, the OPG may want to establish the mental capacity of a patient at a particular time. If healthcare professionals can release this information promptly, it can help ensure these investigations are completed as quickly as possible. If a request from the OPG concerns a patient who has capacity, however, explicit consent for disclosure must be sought from the patient

When should disclosures be made to protect adults who lack capacity?

In the absence of a legal requirement, where adults lack the capacity to make a decision about whether or not to disclose information relating to harm or abuse, decisions need to be made on their behalf. Healthcare professionals can make a decision based upon an assessment of the individual's best interests. When considering a disclosure of information, any assessment of best interests will ordinarily involve discussion with those close to the individual. However, care must be taken to ensure that anyone consulted who is close to the individual is in fact acting in the person's interests. Healthcare professionals must disclose information to the appropriate authority where there is a belief that an adult lacking capacity is at risk of abuse or other serious harm, unless it is not in the overall best interests of the patient to do so.



Key resources

BMA – Confidentiality and health records toolkit

BMA – Best interests decision making for adults who lack capacity toolkit



5

Mental capacity in Northern Ireland



Contents

5.1 Introduction115
5.2 Capacity and incapacity117
5.3 Basic principles118
5.4 Assessing capacity 120
5.5 Best interests
5.6 Supported decision making 124
5.7 Advance decisions to refuse treatment 125
5.8 Treatment in an emergency128
5.9 Treatment requiring special safeguards129
5.10 Restraint and other restrictive practices 131
5.11 Care and treatment amounting to
deprivation of liberty – the Deprivation of Liberty Safeguards regime (DoLS)133
5.12 Research
5.13 Dispute resolution 142
5.14 Confidentiality and information sharing 143



Introduction

The Mental Capacity Act (Northern Ireland) 2016 (MCA(NI)) was enacted by the Northern Ireland Assembly in May 2016, but currently only the sections relating to research, money and valuables, and to deprivation of liberty are in force. Apart from these provisions, the care and treatment of adults lacking capacity in Northern Ireland remains largely governed by the common law, (or, in some cases, the Mental Health (Northern Ireland) Order 1986) with serious interventions potentially requiring High Court Declaratory Orders. This means that some of the general provisions (such as those relating to basic principles, assessing capacity, best interests, and emergency provisions) are 'live' when applied to deprivations of liberty and research, but not for general treatment decisions, where the common law continues to apply. This guidance is aimed at helping doctors to find their way through this complicated legal situation, by setting out clearly which decisions are subject to the rules and tests set out in the common law and which are subject to the statutory rules in the MCA(NI).

Most of the day-to-day decisions doctors make will be covered by the common law and so this forms the majority of this guidance. For decisions relating to deprivations of liberty, or research, where the MCA(NI) applies, the statutory rules and principles are set out in detail in those sections. Although the common law and the MCA(NI) are very similar, it is essential that the correct tests are used when making decisions. Once the MCA(NI) is fully implemented, this guidance will be reissued to reflect those changes.

Under the common law in Northern Ireland, an action or intervention will be lawful (that is, healthcare professionals will enjoy protection from liability) where the decision maker has a reasonable belief that the individual lacks capacity to consent to what is proposed, and the action or decision is in their best interests. In relation to medical treatment, it is applicable not only to an episode of treatment, but also to those necessary ancillary procedures such as conveying a person to hospital.

There are limits to these powers. A valid and effective advance refusal of treatment, for example, is likely to be binding under the common law (and this status will be placed on a statutory footing when the Act is fully in force). There are also limits on the extent to which the freedom of movement of an adult who lacks capacity can be restricted. An adult who lacks capacity can only be restrained where there is a reasonable belief that it is necessary to protect them from harm and the proposed action is proportionate to the risk; where any restriction amounts to a deprivation of liberty, the MCA(NI) must be followed and the action will only be lawful when the appropriate authorisation is in place.

Codes of Practice have been issued for those parts of the MCA(NI) that are currently in force. This includes codes on the deprivation of liberty, and on money and valuables & research. It is essential that healthcare professionals who are making decisions in these areas of practice are familiar with these Codes of Practice.



5.1 2

Key resources

DHNI – <u>Deprivation of Liberty Code of Practice 2019</u>

DHNI – MCA Useful Information and Contacts

DHNI – Mental Capacity Act (Northern Ireland) 2016 (resources)

DHNI – Money and Valuables & Research Code of Practice 2019

Mental Capacity Act (Northern Ireland) 2016



Capacity and incapacity

What is capacity?

Decision-making capacity refers to the everyday ability we possess to make decisions or to take actions that influence our lives, from simple decisions about what to have for breakfast, to complex decisions about serious medical treatment. In a legal context it refers to a person's ability to do something, including making a decision, which may have legal consequences for themselves or for other people.

When does a person lack capacity under the common law?

Under the common law in Northern Ireland (set out in the Appeal Court case of Re MB), a person lacks capacity if:

'some impairment or disturbance of mental functioning renders the person unable to make a decision whether to consent or to refuse treatment'.

An impairment or disturbance of mental functioning could be the result of a variety of factors, including mental illness, learning disability, dementia, brain damage, or intoxication.

An individual lacks the capacity to make a decision if, at the time the decision needs to be made, they are unable to:

- understand the information relevant to the decision;
- retain the information;
- use or weigh the information as part of the process of making a decision;
 or
- communicate the decision.

The assessment of capacity is 'task specific'. It focusses on the specific decision that needs to be made at the specific time the decision is required. It does not matter if the incapacity is temporary, or the person retains the capacity to make other decisions, or if the person's capacity fluctuates.

The MCA(NI) provides a statutory definition of what it means to lack capacity to consent to a deprivation of liberty (section 5.11) or participation in research (section 5.12); see the relevant sections of this guidance when making decisions on those issues.



Basic principles

What are the basic principles of the common law?

The basic principles that apply to decision making for patients who lack capacity are rooted in best practice and the common law and are designed to be compliant with the Human Rights Act. Actions or decisions that clearly conflict with these principles are unlikely to be lawful, although there may be occasions where they are in tension, and some balancing will be required. A list of the basic common law principles, with brief descriptions, is given below:

A presumption of capacity

In Northern Ireland, no one should be treated as lacking capacity unless it has been established that they lack the capacity to make the decision in question. Decision making in this area therefore starts from the position that adults have the right to make decisions on their own behalf and are assumed to have the capacity to do so. This means that it is never for an adult to prove their own capacity. Where a person intends to take steps on the basis that the adult lacks capacity to make the relevant decision, that person must be able to explain why they consider that they are allowed to do so, including why the adult can be said to lack capacity.

The freedom to make an unwise decision

No assumptions about the individual's capacity should be made merely because they are making what others consider to be an unwise decision. Making a rash, unwise or irrational decision, or acting out of character, is not in and of itself proof of incapacity. All adults retain the right to make decisions which seem unwise or irrational to others. Although such actions may raise questions about capacity which require further exploration — where for example they follow a period of illness or an accident — they are not determinative of capacity. What matters is the ability to make the decision, not the content of the decision per se. This means that while an unwise decision might be a reason to consider whether the person has capacity, it cannot be the basis on which they are found to lack capacity.

Necessity and best interests

Under the common law, where individuals lack capacity, no one else, including family members, has the legal authority to consent on their behalf. (There are provisions in the MCA(NI) for individuals to appoint an attorney to make health and welfare decisions on their behalf if they lose capacity, but these have not yet come into force.) Treatment can, however, be provided when it is both necessary to intervene, and the intervention is in the individual's best interests. When assessing an individual's best interests, special regard should be given to statements of current or prior wishes or feelings expressed or made by the individual, and to what is known about the individual's beliefs and values. A determination of what is in the best interests of a person who lacks capacity must not be based solely on the person's age, appearance, or any other characteristic, including any condition. Rather all relevant circumstances must be considered.

For more information about assessing a patient's best interests see section 5.5. The BMA also has a separate toolkit on best interests decision making for adults who lack capacity; although this is based on the legislation in England and Wales, much of the practical information and guidance will also be helpful to doctors practising in Northern Ireland (see key resources).



The less restrictive alternative

Any decisions must be made in compliance with the Human Rights Act 1998. Therefore, whenever a person is making a decision on behalf of an adult who lacks capacity, he or she must consider if it is possible to make the decision in a way that is less restrictive of that individual's fundamental rights or freedoms. There are often several ways to achieve a desired outcome, and where possible the choice must be the one that interferes least with the individual's freedoms while still achieving the necessary goal. The option chosen must, however, be in the person's best interests, which may not in fact be the least restrictive.



Key resources

BMA – Best Interests decision-making for adults who lack capacity. Although this is based on the law in England and Wales, the practical information may also be useful for doctors working in Northern Ireland.



Assessing capacity

Who should assess capacity?

The law does not specify who should assess capacity where a patient's ability to make a decision has been called into question (but see section 5.11 for guidance on assessing capacity for a deprivation of liberty). However, anyone who wishes to carry out an action in connection with the care or treatment of an individual, in their best interests, must have a reasonable belief that they lack the requisite capacity. In its guidance on decision making and consent at paragraph 82 the GMC states:

'Assessing capacity is a core clinical skill and doesn't necessarily require specialist input (eg by a psychiatrist). You should be able to draw reasonable conclusions about your patient's capacity during your dialogue with them. You should be alert to signs that patients may lack capacity and must give them all reasonable help and support to make a decision.'

If you believe that the patient may lack the capacity to make a specific decision, then you must assess their capacity to make the decision in question, as set out below. Where consent to medical treatment is required, the healthcare professional proposing the treatment is responsible for ensuring that the patient has the capacity to consent before proceeding, otherwise, under the common law, they would not be able to rely upon the defence of necessity to justify their actions. If the patient lacks the requisite capacity, the person carrying out the treatment must be satisfied that it is necessary and in the patient's best interests or, again, they could not rely on the defence of necessity to justify their actions.

The reasons why capacity is in doubt should be recorded in the medical record, as should details of the assessment process and its findings. The more serious the decision, the more formal the assessment of capacity is likely to be.

If there is doubt about whether the patient has the capacity to make a specific decision, it can be helpful to seek support from someone who knows the patient well, for example, another member of the healthcare team or someone close to the patient. Although assessing capacity is a core clinical skill, in complex cases, where there is doubt about whether the patient has the requisite capacity, you should seek specialist input from colleagues such as psychiatrists or psychologists. You should also seek specialist input if the patient or someone close to them disagrees with your assessment.

How do you assess capacity?

When assessing an individual's capacity to make a specific treatment decision, doctors should ensure, as far as possible, that any factors likely to affect the patient's ability to decide for themselves are addressed beforehand. These may include medication, medical condition, pain, time of day, fatigue, or mood. Any information must be given as clearly and plainly as possible with communication aids used where appropriate. Those assessing a patient's capacity are also under an obligation to enhance their capacity as far as reasonably possible. This will involve seeking to ensure that patients are engaged in decision making when they are best able to participate and are encouraged to participate in decision making to the greatest extent they are able.



In relation to medical treatment, doctors should follow the common law which states that a person lacks capacity 'if an impairment or disturbance of mental functioning renders them unable to make a decision'. That inability to make a decision occurs when they are unable to:

- understand the information relevant to the decision;
- retain the information;
- use or weight that information as part of the process of making the decision; or
- communicate the decision.

Where an individual fails one or more parts of this test, they do not have the relevant capacity. Difficult judgements will still need to be made, particularly where capacity fluctuates; where some capacity is demonstrable but its extent is uncertain; or where the impairment – which does not require a formal diagnosis – may interact with coercion or duress from those close to the individual.

If the incapacity is temporary and the decision can reasonably be put off until such time as the patient is likely to regain capacity, then it should be deferred.

While it is clear that an unconscious patient will lack capacity, most other patients will retain some decision-making capacity, however slight. In assessing capacity, family members and close friends may be able to provide valuable background information about the individual to assist with the assessment of capacity, although their views about what they might want for the individual must not be allowed to influence the assessment of capacity.

What do you do if an individual refuses to be assessed?

Occasionally an individual whose capacity is in doubt may refuse to be assessed. In most cases, a sensitive explanation of the potential consequences of such a refusal, such as the possibility that any decision they may make will be challenged later, will be sufficient for them to agree. However, if the individual flatly refuses, in most cases no one can be required to undergo an assessment. In these circumstances, doctors should document the refusal in the medical record, make a decision about capacity based on the information they have available, and document the decision reached and the reasons for it; where the question of capacity cannot be resolved on the basis of existing information, legal advice should be sought.

If there are reasonable grounds to believe that the refusal of assessment results from coercion by a third party, legal advice should be sought (see key resources).



Key resources

BMA and The Law Society – <u>Assessment of Mental Capacity. A practical guide for doctors and lawyers (5th edition)</u>. Although this is based on the law in England and Wales, some of the practical information will still be useful for doctors practising in Northern Ireland.

GMC – Decision making and consent



Best interests

What is meant by best interests?

All decisions taken on behalf of someone who lacks capacity in Northern Ireland must be taken in their best interests. Case law, including common law case law, has established that when assessing an individual's best interests, decision makers must look at their welfare in the broadest sense. This must extend beyond medical factors to incorporate social and psychological dimensions of wellbeing.

As part of the assessment process, the Supreme Court applying the English Mental Capacity Act has made it clear that the decision maker must make a reasonable effort to put themselves in the place of the patient and ask what their attitude to the proposed treatment would be. We consider that this approach applies equally to a decision maker applying the common law in Northern Ireland in relation to medical treatment. The focus should therefore be on determining what decision the individual would make if they had the capacity to choose. (See also section 5.6 on supported decision making.)

What should you consider when assessing best interests?

Lacking capacity to make a decision should not exclude an individual from participating in the decision-making process as far as possible. The decision maker must consider whether the person is likely to regain capacity and, if so, whether the decision can reasonably be left until they regain the capacity to make it.

When determining whether an intervention would be in the best interests of an adult who lacks capacity, assumptions must not be made merely on the basis of the individual's age or appearance, their medical condition, or any disability, or an aspect of their behaviour — this is the principle of equal consideration and non-discrimination.

In most circumstances it will be clear where the individual's best interests lie, and a decision as to care or treatment will not be challenging or time-consuming – but this is not always the case. Whether to provide analgesics for someone in pain is likely to be a straightforward question; a decision about whether to continue providing life-sustaining treatment is less so. Where a decision is likely to have grave consequences for a person it will require greater consideration, wider consultation with those close to the patient, and more detailed documented evidence about the decision reached and the reasons for it.

Relevant factors to consider are likely to include (so far as they are reasonably ascertainable):

- the person's past and present wishes and feelings and, in particular, any written statements made when they had capacity;
- their wishes, beliefs, and values; and
- other factors the person would have considered if able to do so, such as the effect of the decision on other people.

For significant decisions, a crucial part of best interests assessments involves discussion with those close to an individual who lacks capacity, including family, friends, or carers, where it is practical or appropriate to do so, bearing in mind the duty of confidentiality (see section 5.14 on information sharing). The BMA has a best interests decision making toolkit which, although based on the legislation in England and Wales, contains a lot of practical information and guidance that may be helpful for those practising in Northern Ireland (see key resources).



Are there any exceptions to the best interests principle?

There are two circumstances in which the best interests principle will not apply. The first is where someone has previously made an advance decision to refuse treatment (ADRT) while they had capacity. Where the advance decision is valid and effective, it should be respected, even if others think that the decision is not in their best interests. For more information on advance decisions see section 5.7. The second exception relates to the enrolment of adults who lack capacity in certain forms of research - see section 5.12.



Key resources

BMA – Best Interests decision-making for adults who lack capacity toolkit. Although this is based on the law in England and Wales, the practical information may also be useful for doctors working in Northern Ireland.



Supported decision making

What does 'supported decision making' mean?

In 2009, the UK ratified the United Nations Convention on the Rights of People with Disabilities (CRPD). Although not incorporated into UK law, and so not part of the law in Northern Ireland, the CRPD has ushered in something of a sea-change regarding the care and treatment of people who may lack capacity to make certain decisions. The focus of the CRPD is on *supported* rather than *substitute* decision making. In this section we set out ways in which doctors can draw on aspects of this approach to complement their obligations under the common law.

Is there a difference between mental and legal capacity under the CRPD?

Yes. Although mental and legal capacity are treated similarly under mental capacity law, the CRPD relies on a distinction between mental and legal capacity. Legal capacity refers to the formal ability to hold and exercise rights and duties. Under the CRPD, these are universal and cannot be lost. Mental capacity refers to decision-making skills and abilities and these clearly vary from individual to individual.

What does 'supported decision making' mean under the CRPD?

As interpreted by the UN treaty body responsible for the CRPD, the Convention uses the concept of supported decision making in a particular sense. It requires ensuring that people receive the support they need and want to make and express decisions where this is possible. If it is not possible, decisions must be taken in a way that reflects the person's 'will and preferences.' Where their will and preferences are unclear, it is permissible to act according to a 'best interpretation of will and preferences.' This approach now guides decisions made by the Court of Protection in England and Wales (which courts in Northern Ireland are likely to look to when considering cases), and the Supreme Court (whose decisions form case law in Northern Ireland). The key difference is that the focus is increasingly on determining what the individual would want — and consider to be in their best interests — in the circumstances, rather than what others believe objectively to be in their best interests.

What measures can enhance supported decision making?

These measures can include:

- exploring with the person how best they can be supported to make decisions;
- identifying, as far as possible, the wishes and feelings of those unable to make decisions. Such wishes and feelings should be complied with when making best interests decisions unless there are compelling reasons to set them aside;
- ensuring facilities are available in healthcare services where assessments
 of capacity are frequent to ensure the proper support of those being
 assessed, including an environment conducive to their maximal
 involvement in decision making; and
- facilitating, as appropriate, the involvement of those close to the individual to support their decision making.

Who is responsible for ensuring appropriate support?

The obligation to take appropriate steps to support the person to make a decision falls largely on those responsible for assessing the individual's mental capacity. This will include ensuring a conducive environment and ensuring information is provided in an accessible form.



Advance decisions to refuse treatment

Are advance decisions to refuse treatment legally binding?

When the MCA(NI) is fully enacted it will provide a statutory foundation for advance decisions to refuse treatment (ADRT), such that where there is a valid and effective ADRT made by an adult, this will be legally binding. Currently, however, there is no legislation in force covering ADRTs in Northern Ireland. The Department of Health's review of the law relating to ADRTs (see key resources) says that 'Valid and effective advance decisions to refuse treatment have the same legal status as decisions made by people with capacity'. It states that before healthcare professionals apply an ADRT there must be proof that:

- 'a. The decision exists (this is more likely to be apparent if the decision is in writing):
- b. The decision applies to the existing circumstances;
- c. The person had capacity to make the decision at the time it was made;
- d. The person making the decision understood the consequences of refusing treatment; and
- e. The person making the decision was not under the undue influence of a third party.'

It goes on to state that in order to establish whether an ADRT is valid and effective, healthcare professionals must try to ascertain whether the person making it:

- `a. Has done anything that clearly goes against their advance decision;
- b. Has withdrawn their decision;
- c. Has subsequently conferred the power to make that decision on an attorney; or
- d. Would have changed their decision if they had known more about the current circumstances.'

When assessing the validity of an ADRT it is important to remember the principle that no one should be treated as lacking capacity unless it has been established that they lack the capacity to make the decision in question (see section 5.3). Doctors should therefore start from the presumption that a person who has made an advance decision had the capacity to make it, unless there are reasonable grounds to doubt the person had the capacity to make the advance decision at the time they made it. In cases of genuine doubt about the existence or validity of an advance decision, doctors can provide treatment that is immediately necessary to stabilise or to prevent a deterioration in the patient's condition until the existence, and the validity and effectiveness, of the advance decision can be established. If doubts cannot be resolved locally, and time permits, legal advice should be sought about applying to the court for a declaration.

Advance requests for future treatment, or statements about matters other than medical treatment, are not legally binding, although they can be a very useful indication of a patient's wishes and feelings when making best interests decisions.



Are there limits to advance decisions to refuse treatment?

Although any written or oral statements of patients' future wishes are clearly a vital part of decision making, there are limits to patients' ability to influence their future care. Nobody can authorise or refuse in advance procedures they could not authorise or refuse contemporaneously. They cannot, for example, insist upon treatment that is not clinically indicated. In the BMA's view, it would also be inappropriate for patients to refuse in advance the provision of all forms of 'basic care' such as hygiene and interventions designed solely for the alleviation of pain or distress. This also includes the offer of oral food and water (but not clinically-assisted nutrition and hydration). An advance decision to refuse treatment cannot be used to nominate someone else to make decisions, or give effect to an unlawful act.

Do advance decisions apply to individuals subject to compulsory mental health legislation?

Advance decisions to refuse treatment cannot extend to treatment for mental disorders provided under the authority of the Mental Health (Northern Ireland) Order 1986. The Department of Health's policy on advance care planning, however, says: 'When the Mental Capacity Act (Northern Ireland) 2016 is fully commenced it will replace the Mental Health (NI) Order 1986, for everyone aged 16 and over, and will include mental health treatment. The Mental Capacity Act NI 2016 will provide a statutory foundation for an ADRT. It will note that if there is a valid and applicable ADRT, this cannot be overruled by a decision under the Act' (see key resources).

Is there a specific format for advance decisions to refuse treatment?

The common law does not set out the form in which an advance decision to refuse treatment needs to be made. Oral advance decisions can be binding, particularly when supported by appropriate evidence, although a note should be made of any such oral decision in the medical record. It is worth bearing in mind that advance decisions can also be recorded, for example on smart phones, although patients have to take appropriate steps to ensure relevant people are made aware of their existence.

Patients wishing to make an advance decision that is likely to have serious consequences for them, including any decision relating to life-sustaining treatment, should ideally put their wishes in writing. (It is worth noting that the Mental Capacity Act for England and Wales requires any decision relating to life-sustaining treatment to be in writing, signed and witnessed, and to contain a statement that it is to apply even where life is at risk, and this could be considered best practice when patients are drawing up an ADRT).

In the BMA's view, patients making a written advance decision should include the following:

- full details of the person making the advance decision including their name and address:
- the name and address of the person's GP and whether they hold a copy of the document;
- a statement that the document should be used if the person ever lacks capacity to make treatment decisions;
- a clear statement of the decision, the treatment to be refused and the circumstances in which the decision will apply;
- the signature of the person making it and any person witnessing the signature; and
- the date the document was written or subsequently reviewed.



It is advisable for patients to review their ADRTs regularly, particularly where there are any material changes in the individual's condition or treatment options, and at least every five years.

How should advance decisions be stored?

The storage of advance decisions, and the obligation to ensure that relevant healthcare professionals are aware of them, are the responsibility of those who make them. A copy of any written ADRT should be given to the patient's GP for storage in the medical record; a copy of the document should be provided to another healthcare professional involved in the patient's care on request. The patient should also draw it to the attention of hospital staff before an episode of care. It is also good practice for anyone who makes an ADRT to draw it to the attention of anyone who may be called upon to contribute to best interests assessments, such as friends, family, or any advocate.



Key resources

DHNI – For now and the future. An advance care planning policy for adults in Northern Ireland

DHNI – Review of the law relating to Advance Decisions to Refuse Treatment



Treatment in an emergency

Can emergency treatment be provided to adults who lack the capacity to consent?

It is clearly established under the common law 'principle of necessity' that, in an emergency, where consent cannot be obtained, doctors should provide treatment that is immediately necessary either to preserve life or to prevent a serious deterioration in the patient's condition. The only exception to this is where there is clear evidence of a valid and effective advance decision refusing the treatment in question (see section 5.7). Emergency treatment does not have to be restricted to what is immediately necessary. Applying the principles set out above, to consider the person's capacity and best interests, it can also include steps to prevent deterioration in order to ensure that recovery is an option. Where decisions can reasonably be delayed until such time as the adult is likely to regain capacity, or to permit an assessment of capacity and discussion with those close to the patient, then they should be.

What should you do if, in an emergency, a patient refuses treatment and there is doubt as to their capacity?

Doctors should take whatever steps are necessary to prevent deterioration in the patient's condition, and then consider questions of capacity and consent. If it is clear that a patient has the capacity to refuse treatment, or has a valid and effective advance decision to refuse the treatment, doctors cannot provide the treatment unless authorised under the Mental Health (Northern Ireland) Order 1986. For more information on advance decisions to refuse treatment, see section 5.7.

What should I do if emergency treatment amounts to a deprivation of liberty?

The emergency provisions in the MCA(NI) are in force in relation to decisions about deprivation of liberty. Chapter 10 of the Deprivation of Liberty Safeguards (DoLS) Code of Practice (see key resources) explains the process that must be followed in an emergency situation.



Key resources

DHNI – <u>Deprivation of Liberty Safeguards Code of Practice</u> 2019



Treatment requiring special safeguards

For most day-to-day healthcare decisions, the procedures and principles set out in the common law and outlined in this guidance are sufficient. There are some treatments, however, that are generally regarded as being more serious or controversial and require either special safeguards, or in the case of the most complex and difficult decisions, referral to court.

What treatments may require an application to the court?

In England, case law (including Supreme Court case law) and Court of Protection guidance have made clear that certain categories of cases are ones where legal advice should be sought to determine whether an application to court is required. Given that these are cases where there is doubt or disagreement about the correct course of action, or where it is considered that the proposed treatment would involve serious interference with the person's human rights, the BMA recommends that doctors in Northern Ireland seek legal advice in cases, where:

- at the end of the decision-making process:
 - the decision is finely balanced;
 - there is a difference of medical opinion;
 - there is a doubt or dispute that cannot be resolved locally (see section 5.13) about whether a particular treatment will be in a person's best interests; or
 - there is a conflict of interest on the part of those involved in the decision-making process that cannot be appropriately managed;
- a medical procedure or treatment is for the primary purpose of sterilisation;
- the procedure is for the purpose of donation of an organ, bone marrow, stem cells, tissue, or bodily fluid to another person;
- the action proposed involves a procedure for the covert insertion of a contraceptive device or other means of contraception;
- it is proposed that an experimental or innovative treatment be carried out;
 or
- the case involves a significant ethical question in an untested or controversial area of medicine.

It is also advisable to seek legal advice where the proposed action involves the use of deception to deliver medical treatment (for example covert medication) to the patient on a regular or long-term basis.

Is Court approval required for decisions relating to the proposed withholding or withdrawal of clinically-assisted nutrition and hydration (CANH) from patients in a persistent vegetative state or a minimally conscious state?

The Supreme Court has made clear that there is no legal obligation to seek Court approval for these decisions unless, at the end of the best interests assessment:

- the way forward is finely balanced;
- there is a difference of medical opinion;
- there is a lack of agreement to a proposed course of action from those with an interest in the patient's welfare; or
- there is a potential conflict of interest on the part of those involved in the decision-making process that cannot be appropriately managed.





The BMA and Royal College of Physicians (RCP) have produced joint guidance on making decisions about CANH for adults who lack capacity which, although based on the law in England and Wales, may also provide useful practical advice for doctors working in Northern Ireland (see key resources).

Key resources

Applications relating to medical treatment; guidance authorised by the Honourable Mr Justice Hayden, the Vice-President of the Court of Protection

BMA and RCP – <u>Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent. Guidance for decision-making in England and Wales.</u> Although this is based on the law in England and Wales, some of the practical information will still be useful for doctors practising in Northern Ireland.



Restraint and other restrictive practices

What is restraint?

There may be occasions when healthcare professionals need to consider the use of restraint in treating an individual lacking capacity. Restraint is the use or threat of force, to make someone do something they are resisting, or restricting a person's freedom of movement, whether they are resisting or not. Healthcare professionals have a common law right to use proportionate restraint to prevent the immediate risk of harm to the patient or others.

Any use of restrictive practices, including the use of restraint, should comply with the NI Department of Health's *Regional policy on the use of restrictive practices in health and social care settings* (see key resources). If restraint amounts to a deprivation of liberty, the required legal authority must be in place for the action to be lawful (see section 5.11).

What are the types of restraint?

Restraint can be overt, such as the use of bed rails. It can also be covert and indirect such as having doors that are heavy and difficult to open or putting patients in low chairs from which they find it difficult to move. The Regional Policy defines restraint as including:

'Physical Restraint: Any direct physical contact where the intervener prevents, restricts or subdues movement of the body, or part of the body, of another person.

Mechanical Restraint: The use of a device to prevent, restrict or subdue movement of a person's body, or part of the body, for the primary purpose of behavioural control.

Chemical Restraint: The use of medication, which is prescribed and administered for the purposes of controlling or subduing acute behavioural disturbance, or for the management of on-going behavioural disturbance.'

What other types of restrictive practices are there?

In addition to restraint, restrictive practices are defined in the Regional Policy as including:

Environmental restrictions: The use of obstacles, barriers or locks to prevent a person from moving around freely. This could also include the use of electronic monitoring.

Psychological restrictions: Depriving a person of choices, controlling them through not permitting them to do something, making them do something or setting limits on what they can do.

Coercion: The practice of persuading someone to do something by using force or threats.

Observation: A restrictive intervention of varying intensity in which a member of healthcare staff observes and maintains contact with a person to ensure the person's safety and the safety of others.'

Seclusion is defined as 'the confinement of a person in a room or area from which free exit is prevented.'



When is the use of restrictive practices permitted?

The Regional Policy sets out the following general principles which must apply to any use of restrictive practices.

- Decisions to use restrictive practices must be supported by robust justification.
- Children and young people should never be subject to seclusion.
- Restrictive interventions, restraint and seclusion should not be used for reasons related to disability.
- Any use of restrictive practices must only be considered as a last resort.
- Initial attempts of restraint should as far as possible be non-physical.
- There must be a real possibility of imminent harm to the person or to staff, the public or others if no action is undertaken.
- Any use of restrictive practice must be most effective and therapeutic intervention possible with regards to reducing behaviours associated with risk and/or their impact.
- The nature of the technique used must be proportionate to the risk of harm and the seriousness of that harm and be the least restrictive option that will meet the need.
- Any restriction should be imposed for no longer than absolutely necessary.
- Restrictive interventions, restraint or seclusion must never be used as
 discipline, to inflict pain or humiliation, or a substitute for the provision of
 proper, person-centred care.
- Use of restraint or seclusion must be considered in the context of the legal authority for its use, and fully compliant with a rights-based approach.'

If these conditions are met, it is permissible to use restrictive practices to provide necessary treatment to an individual. It also follows that in such circumstances there would be no liability for assault. Where, however, the practices amount to a deprivation of liberty (see section 5.11), the action would be unlawful unless the necessary authorisation has been obtained.



Key resources

DHNI – Regional policy on the use of restrictive practices in health and social care settings, March 2023



Care or treatment amounting to a deprivation of liberty – the Deprivation of Liberty Safeguards regime (DoLS)

What is a deprivation of liberty?

It may be necessary at times to provide care or treatment to an adult lacking capacity in circumstances that amount to a deprivation of their liberty. The acid test to determine whether what is being done to the person is a deprivation of liberty is that the person is:

- not free to leave; and
- under continuous supervision and control.

The Deprivation of Liberty Safeguards (DoLS) Code of Practice (see key resources) provides guidance as to the meaning of deprivation of liberty and is accompanied by a set of scenarios. Deprivations of liberty can be authorised if they comply with the deprivation of liberty safeguards; these only apply to people who are aged 16 years old or over who are in a place where care or treatment is being provided.

If a person has capacity to consent, they can be subject to any arrangements, including arrangements that are of a similar nature to a deprivation of liberty, on a voluntary basis. However, if he or she, at any time, loses capacity to consent, such arrangements are no longer voluntary. If a person no longer has capacity to consent to the arrangements, all the safeguards of the MCA(NI) must immediately be put in place. The DoLS Code of Practice is clear (at paragraph 2.11) that a 'person who has capacity cannot consent pre-emptively to the deprivation of their liberty for a time in the future when they may no longer have capacity'.

No deprivation of liberty will be deemed to have occurred – and therefore no authorisation will be required – where the person is in hospital being treated for a life-threatening illness and the circumstances of the treatment for the physical illness for the person who lacks capacity is the same as for a person who has capacity.

The DoLS Code of Practice, reflecting case law from England and Wales, clarifies that this situation would apply to:

'a person in intensive care who is chemically restrained due to the physical illness they are being treated for, and thus not free to leave and is subject to continuous supervision and control. However, if the reason for the restraint is the physical illness and not the lack of capacity, the person is not deprived of his or her liberty and the additional safeguards outlined in this Code do not apply.' (paragraph 2.21)

What is meant by 'not free to leave'?

The DoLS Code of Practice makes clear that the fact that the individual is unable to leave does not necessarily mean that the individual is being prevented from leaving which would amount to a deprivation of liberty. Examples of the type of situations which would require authorisation include:

- locked doors that are not unlocked on the individual's request;
- physically preventing the individual from leaving;
- the individual not being able to leave the place without supervision; and
- not being free to permanently move residence.



What is 'continuous supervision and control'?

The DoLS Code of Practice says that being under 'continuous supervision and control' may include having control over who the patient can have contact with, control over their activities, or supervision over their health and actions. In practical terms, when considering whether an individual is subject to 'continuous supervision and control', it can be helpful to ask whether there is a care plan in place that means that those looking after the individual will be aware at any time:

- where the individual is:
- what the individual will be doing;
- who the individual will have contact with; and
- what steps they will take if they cannot establish the above.

What is the legal basis for a deprivation of liberty?

The MCA(NI) and the Mental Capacity (Deprivation of Liberty) (No. 2) Regulations (Northern Ireland) 2019 set out a process for the authorisation of a deprivation of liberty for those people aged 16 and over lacking capacity to consent to the arrangements. These provisions combined form the Deprivation of Liberty Safeguards (DoLS). The basic features of DoLS are given below to give an overview of the system. Those who are, or are likely to be, required to make or participate in decisions about deprivation of liberty must familiarise themselves with the DoLS Code of Practice and training requirements (see key resources). It is also necessary that they are familiar with the situations under which the Mental Health (Northern Ireland) Order 1986 may apply because, where it does apply, the law is clear that the Order must be used rather than the DoLS framework.

It is very important also to understand that a DoLS authorisation does not give any authority to carry out acts of care and treatment. Care and treatment therefore need to be delivered either on the basis of the person's capacitous consent, or on the basis of the common law approach (see sections 5.2.5.3, and 5.5)

What principles apply to decisions that include deprivation of liberty?

The principles set out in the MCA(NI) have been 'live' in relation to deprivations of liberty since 2019. It is important that the statutory principles are used, and where necessary are referred to expressly, when making decisions relating to deprivation of liberty.

The statutory principles are as follows:

'Principle 1-A person is not to be treated as lacking capacity unless it is established that the person lacks capacity in relation to the matter in question.

Principle 2- The question if a person is able to make a decision for himself or herself can only be determined by considering the requirements of the Act and no assumptions can be made merely on the basis of any condition that the person has or any other characteristics of the person.

Principle 3 – A person is not to be treated as unable to make a decision for himself or herself unless all practicable help and support to enable the person to make the decision has been given without success.

Principle 4 – A person is not to be treated as unable to make a decision merely because the person makes an unwise decision.

Principle 5 – Any act done, or decision made, must be made in the person's best interests.'



What are the deprivation of liberty safeguards?

Before a person can be deprived of their liberty the following safeguards must be in place:

General safeguards

To be protected from liability when depriving a person of his or her liberty, there must be:

- a reasonable belief of lack of capacity; and
- a reasonable belief of best interests.

Additional safeguards

Four additional safeguards must also be in place for the deprivation of liberty to be lawful:

- a formal assessment of capacity must be completed;
- the nominated person should be consulted;
- the prevention of serious harm condition must be met; and
- an appropriate authorisation must be in place (see below).

What is the test of capacity for deprivation of liberty?

The test of capacity in the MCA(NI) has been 'live' in relation to deprivation of liberty since 2019 and therefore must be used, and where appropriate, explicitly referred to. For the purposes of deprivation of liberty, an individual lacks capacity if they are:

'unable to make a decision for himself or herself about the matter, because of an impairment of, or a disturbance in the functioning of, the mind or brain.'

There are three elements to the assessment of capacity:

- 1. an inability to make a decision (the functional test);
- 2. an impairment of, or a disturbance in the functioning of the mind or brain (the impairment/disturbance test); and
- 3. a causal link between the two (ie the inability to make a decision must be caused by the impairment).

All three elements are equally important, and all three elements must be present for the person to lack capacity.

The DoLS Code of Practice states that, under the functional test, an individual lacks the capacity to make a decision if they are unable to do any of the following:

- 'a. understand the information relevant to the decision (which includes information about the reasonably foreseeable consequences of deciding one way or another or failing to make the decision);
- b. retain that information for the time required to make the decision;
- c. appreciate the relevance of that information and use and weigh it as part of the decision making process;
- d. communicate his or her decision.'



Who can carry out a formal assessment of capacity for a deprivation of liberty?

The DoLS code of practice states that a formal assessment of capacity, and a statement of incapacity, for a deprivation of liberty may be carried out by any of the following people:

- a. social worker;
- b. medical practitioner;
- c. nurse or midwife;
- d. occupational therapist;
- e. speech and language therapist;
- f. dentist:
- g. practitioner psychologist.

In addition, a person carrying out a formal assessment of capacity must:

- have received training on formal capacity assessments approved by the Department of Health within the 36 months immediately prior to the assessment taking place;
- have at least two years' experience in working with persons who lack capacity; and
- must be designated by his or her employer as a person to carry out formal assessments of capacity.

How are best interests assessed in the case of deprivation of liberty?

The sections of the MCA(NI) that apply to best interests decision making have been 'live' in relation to decisions about deprivation of liberty since 2019. It is important that the statutory provisions are followed when making assessments relating to deprivation of liberty.

The code of practice makes clear that the best interests determination:

"... is more than a clinical or medical best interests test; it is a holistic consideration of all relevant factors that would be reasonable to consider under the circumstances. The best interests is not what the professional would do or agree to if he or she was in the same shoes or what the relatives think they would do. A best interests determination starts with consideration of what decision P would have made if P had capacity to make the decision." (para 6.3)

Section 7 of the MCA(NI) sets out factors that must be considered as part of the best interests assessment, although this list is not exhaustive and all relevant points must be considered. The statutory checklist includes that the decision maker must:

- give 'special regard' to (as far as they are ascertainable):
 - the person's past and present wishes and feelings (in particular any written statements made when they had capacity);
 - any beliefs and values that are likely to influence their decision if they had capacity; and
 - any other factors that would be likely to influence their decision;
- not make assumptions merely on the basis of the individual's age, appearance, medical condition or any aspect of their behaviour which might lead others to make unjustified assumptions about what might be the individual's best interests;
- consider all the relevant circumstances;
- encourage and help the individual to participate as fully as possible in the determination of what would be their best interests;



- consider whether the individual is likely to have capacity to make the decision in the future and, if so, when that is likely to be;
- so far as it is practicable and appropriate to do so, consult the relevant people, including the 'nominated person', about what would be in the individual's best interests and take into account those views;
- consider whether the same purpose can be as effectively achieved in a way that is less restrictive of the individual's rights and freedom of action; and
- have regard to whether failure to take the action proposed is likely to result in harm to others with resulting harm to the person lacking capacity.

In relation to the point above, the Code of Practice gives the example that 'resulting harm to [the individual] includes indirect harm such as losing contact with people or being subject to the criminal justice system because of harm caused to others'. It is, however, always important to be able to explain why the person, themselves, will be harmed in consequence.

Who is the 'nominated person'?

The Act requires a 'nominated person' to be consulted when making best interests assessments in relation to proposed actions that would amount to a deprivation of liberty. The nominated person does not have decision-making powers but must be consulted as part of the assessment process.

- A person over 16 years old who has capacity may appoint, in writing, someone over the age of 16 to be their nominated person.
- A person over 16 years old who has capacity may also specify, in writing, that a particular person is not to be their nominated person.
- In some circumstances, the Review Tribunal (an independent judicial body set up by the Mental Health (Northern Ireland) Order 1986) can appoint a nominated person.
- Where neither the individual nor a Review Tribunal has appointed a nominated person the 'default list' will apply. The person who is highest up the list (see below) is the individual's nominated person unless they are under 16 or have been discounted by the individual or the Review Tribunal.

The default list, in order of hierarchy, is set out in section 73 of the Act, as follows:

- a. carer;
- b. spouse or civil partner;
- c. living with the individual as spouse or civil partner for at least 6 months;
- d. child;
- e. parent;
- f. brother or sister;
- g. grandparent;
- h. grandchild;
- i. aunt or uncle;
- j. niece or nephew;
- k. someone living with the individual for a period of at least 5 years.

More information can be found in the DoLS Code of Practice.



How is a deprivation of liberty authorised?

There are two ways of authorising a deprivation of liberty. If a person who lacks capacity is in hospital, a deprivation of liberty — called a short-term detention — can be authorised for the purposes of examination in hospital, or examination followed by treatment and care, on the production of a report from an appropriate healthcare professional, usually an approved social worker, which must include a report from a medical practitioner. The short-term detention can initially be authorised for up to 14 days, then extended for a maximum of a further 14 days.

If a deprivation of liberty happens outside hospital, a panel appointed by the Trust for these purposes must authorise the deprivation. The Trust Panel is made up of three members, one of whom is always a medical practitioner.

Both a short-term detention and a deprivation of liberty authorised by the Trust Panel can be reviewed by the Review Tribunal on the application of the individual or their nominated person.

The DoLS Code of Practice explains the process that must be followed in emergency situations.



Key resources

DHNI - Deprivation of Liberty Safeguards Code of Practice 2019

DHNI - Mental Capacity Act Training

DHNI – MCA Useful Information and Contacts

Mental Capacity Act (Northern Ireland) 2016

Mental Capacity (Deprivation of Liberty) (No. 2) Regulations

(Northern Ireland) 2019



Research

Can patients who lack capacity participate in research?

Yes. The research provisions of the MCA(NI) have been in force since 2019. It is therefore important that the statutory provisions are used and, where appropriate, expressly referred to when making decisions relating to research in Northern Ireland.

Under the MCA(NI) and the Mental Capacity (Research) Regulations (Northern Ireland) 2019, it is lawful to involve adults who lack capacity in research in some circumstances. (Different rules apply to participation in clinical trials — see below). The Money and Valuables & Research Code of Practice (see key resources) sets out the conditions that must apply:

- 'a. it must be connected with the condition which is the cause or contributed to an impairment of, or a disturbance in the functioning of, the mind or brain ("impairing condition") or its treatment;
- there must be reasonable belief that research of comparable effectiveness cannot be carried out if the project has to be confined, or relate, to persons who have capacity to consent only;
- c. it must have the potential to benefit the individual and that the burden
 of the research project is proportionate to the benefit or be intended to
 provide knowledge of causes or treatment, or care, of persons affected by
 same or similar conditions as the individual;
- d. nothing can be done to the individual to which they appear to be objecting except for where the act is done to prevent harm or to reduce pain or discomfort;
- e. nothing can be done to the individual which is contrary to an effective advance decision to refuse treatment;
- f. nothing can be done to the individual which is contrary to a written statement made by the individual when they had capacity; and
- g. if the individual indicates (in any way) a wish to be withdrawn from the project, they must be withdrawn without delay'

In order for research involving patients who lack capacity to be lawful, the interests of the patient must at all times be assumed to outweigh any benefits to science and society.

Clinical trials under Medicines for Human Use (Clinical Trials) Regulations 2004 are subject to their own rules and regulations and guidance should be sought from professional bodies, and health and social care guidance, before such trials are carried out. (In April 2014, the EU adopted the Clinical Trials Regulations 2014 to repeal the earlier Directive on which the 2004 Regulations are based. However, it had not become applicable in the EU when the UK exited the EU and will therefore only be incorporated into UK law if specific, domestic steps are taken to bring this about.)

What principles apply to decisions related to research involving patients who lack capacity?

The principles set out in the MCA(NI) came into force in 2019. It is important that the statutory principles are used and, where appropriate, are expressly referred to when making decisions relating to research.



The statutory principles that apply to decisions about research are listed in the Money and Valuables & Research Code of Practice as follows:

- 'Principle 1 A person is not to be treated as lacking capacity unless it
 is established that the person lacks capacity in relation to the matter in
 question.
- Principle 2 The question if a person is able to make a decision for himself or herself can only be determined by considering the requirements of the Act and no assumptions can be made merely on the basis of any condition that the person has or any other characteristics of the person.
- Principle 3 A person is not to be treated as unable to make a decision for himself or herself unless all practicable help and support to enable the person to make the decision has been given without success.
- Principle 4 A person is not to be treated as unable to make a decision merely because the person makes an unwise decision.
- Principle 5 Any act done, or decision made, must be made in the person's best interests.'

What is the test of capacity for participation in research?

The test of capacity in the MCA(NI) has been 'live' in relation to research since 2019 and therefore must be used, and where appropriate, explicitly referred to. For the purposes of research, an individual lacks capacity if they are:

'unable to make a decision for himself or herself about the matter, because of an impairment of, or a disturbance in the functioning of, the mind or brain.'

There are three elements to the assessment of capacity:

- 1. an inability to make a decision (the functional test);
- 2. an impairment of, or a disturbance in the functioning of the mind or brain (the impairment/disturbance test); and
- 3. a causal link between the two (ie the inability to make a decision must be caused by the impairment).

All three elements are equally important, and all three elements must be present for the person to lack capacity.

The DoLS Code of Practice states that, under the functional test, an individual lacks the capacity to make a decision if they are unable to do any of the following:

- 'a. understand the information relevant to the decision (which includes information about the reasonably foreseeable consequences of deciding one way or another or failing to make the decision);
- b. retain that information for the time required to make the decision;
- c. appreciate the relevance of that information and use and weigh it as part of the decision making process;
- d. communicate his or her decision.

What safeguards exist for individuals who lack capacity in research?

For research involving an adult who lacks capacity to be lawful, it must be approved by an appropriate body recognised by the Department of Health, such as the ethics committee of a university or health and social care trust. The current statutory list of appropriate bodies is set out in the Mental Capacity (Research) Regulations (Northern Ireland) 2019 (as amended) (see key resources).



After receiving approval for a research project, but before commencing the research, the researcher must consult with a person who is engaged in caring for, or is interested in, the patient's welfare on what their wishes and feelings would be if they had capacity. This person cannot be engaged with the patient in a professional capacity. The person can be an attorney under an existing Enduring Power of Attorney, a deputy or the patient's nominated person (see section 5.11). If the researcher is unable to identify anyone willing to be consulted, they must appoint a person who is prepared to be consulted on the project and has no connections with the research.

If, at any time, the person consulted is of the opinion that the patient no longer wishes to take part in the research, the researcher must withdraw the patient from the research.

Can research take place in an emergency where the patient lacks capacity?

Any research, including urgent research, must be approved by an appropriate body recognised by the Department of Health (see The Mental Capacity (Research) Regulations (Northern Ireland) 2019 (as amended)). If the researcher considers it necessary to take action for the purposes of the research, but it is not practicable to consult with others, the researcher can provide the treatment if:

- the researcher has the agreement of a medical practitioner who is not involved in the organisation or conduct of the research project; or
- if it is not practicable to get that agreement, the researcher acts in accordance with a procedure agreed by the appropriate body when the research was approved.

In December 2006, an amendment to the 2004 Clinical Trials Regulations introduced provisions enabling patients to be enrolled in clinical trials of pharmaceutical products without prior consent in emergency situations where the research is approved by an appropriate research ethics committee.

Given the potential vulnerability of adults lacking capacity who are enrolled in research, it is important that doctors undertaking such research are familiar with the substantial body of guidance reflecting international standards for research involving patients who lack capacity.

Can doctors provide innovative treatment to patients lacking the capacity to consent to it?

Doctors have always modified methods of investigation and treatment in light of experience and so innovative therapy is a standard feature of good care. There are occasions however where innovative treatment may involve exposing patients to significant risk. Where adults lack the capacity to consent to innovative treatment, any such treatment must be governed by the MCA(NI) and, in particular, it must be in the person's best interests. Where any proposed treatment differs significantly from existing practice and involves unknown or significant risk, considerable care must be taken as innovation can give rise to legal and ethical uncertainty. In these circumstances, it is advisable to seek both expert clinical scrutiny and legal advice.



Key resources

DHNI – <u>Money and Valuables & Research Code of Practice</u> 2019

The Mental Capacity (Research) Regulations (Northern Ireland) 2019 (as amended)



Dispute resolution

When can disputes occur?

There may be occasions in relation to the care and treatment of a person who may lack capacity where disagreements with the relatives and carers of the patient arise. These may relate to:

- whether an individual retains the capacity to make a decision;
- whether a proposed decision or intervention is in the person's best interests; or
- whether the decision or the intervention is the most suitable of the available options.

It is clearly in everybody's interests that disagreements are resolved as soon as possible, and with as much consensus as possible. Broadly speaking, disputes can be resolved either informally or formally. Some disputes will be so serious that it may be necessary to make an application to court.

How should a dispute be approached initially?

Many disputes can either be avoided, or settled rapidly, by using good communication and involving all relevant individuals. Where healthcare professionals are involved in a dispute with those close to a person who lacks capacity it is a good idea to:

- set out the different options in a way that can be clearly understood;
- invite a colleague to talk the matter over and offer a second opinion;
- consider enrolling the services of an advocate; and/or
- arrange a meeting to discuss the matter in detail.

When should mediation be considered?

Where the methods outlined above do not successfully resolve the dispute, it may be helpful to involve a mediator. Any dispute that is likely to be settled by negotiation is probably suitable for mediation. A mediator is an independent facilitator. It is not the role of a mediator to make decisions or to impose solutions. The mediator will seek to facilitate a decision that is acceptable to all parties in the dispute.

What if a complaint is made?

It may be that as part of the dispute resolution process, those acting on behalf of an adult who lacks capacity might wish to lodge a complaint about the services they have received. Healthcare professionals should be able to provide information about the formal NHS complaints process.

What role does the court have?

If agreement cannot be reached in a reasonable period, legal advice should be sought, and it may be necessary to seek a court order. Where this is the case, relatives and carers of the patient, and where possible, the patient, should be informed and advised to seek legal representation.

Going to court can be distressing for those concerned. However, the benefits are that a court can give rulings very quickly when necessary, and it can provide a protective role for both patients and the healthcare team who treat them in cases where there is a disagreement that cannot be resolved.



Confidentiality and information sharing

Is a duty of confidentiality owed to patients who lack capacity?

Yes. Healthcare professionals owe the same duty of confidentiality to all their patients whether or not they have capacity. Healthcare professionals may therefore usually only disclose information about an adult who lacks capacity where it is in the patient's best interests.

What role do relatives, carers, and friends have?

If a patient lacks capacity, healthcare professionals may need to share information with relatives, friends, or carers to enable them to provide information to help assess the patient's best interests. 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 had not given explicit consent. This does not however mean that all information should be routinely shared. Where the information is particularly 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.

Is there a role for 'next of kin'?

Despite the widespread use of the phrase 'next of kin' this is neither defined, nor does it have formal legal status in relation to decision making about medical treatment. A 'next of kin' has no rights of access to a patient's medical records or to information on a patient's medical condition. On the other hand, if, prior to losing capacity, a patient nominates an individual and gives authority for their condition to be discussed with them, they can provide valuable information.

There are no rules about who can and cannot be nominated as someone to be consulted. A patient may nominate their spouse, partner, member of their family, or friend. In the absence of a named individual, the healthcare team should consult with people who are close to the patient; depending on the seriousness and implications of the decisions to be made, this may be a group of people rather than one individual.

When should disclosures be made to protect adults who lack capacity?

In the absence of a legal requirement, where adults lack the capacity to make a decision about whether or not to disclose information relating to harm or abuse, decisions need to be made on their behalf. Healthcare professionals can make a decision based upon an assessment of the individual's best interests. When considering a disclosure of information, any assessment of best interests will ordinarily involve discussion with those close to the individual. However, care must be taken to ensure that anyone consulted who is close to the individual is in fact acting in the person's interests. Healthcare professionals must disclose information to the appropriate authority where there is a belief that an adult lacking capacity is at risk of abuse or other serious harm, unless it is not in the overall best interests of the patient to do so.



Key resources

BMA – Confidentiality and health records toolkit.

BMA – Best interests decision making for adults who lack capacity toolkit. Although this is based on the legislation in England and Wales much of the practical information and guidance will also be helpful to doctors practising in Northern Ireland.



6

Adults with Incapacity Scotland



Contents

6.1 Introduction146
6.2 Capacity and incapacity147
6.3 Basic principles148
6.4 Assessing incapacity149
6.5 Benefit
6.6 Certificate of incapacity and general authority to treat 154
6.7 Proxy decision makers 156
6.8 Powers of Attorney 158
6.9 Guardianship and intervention orders 160
6.10 Advance statements refusing treatment161
6.11 Treatment in an emergency 163
6.12 Treatment requiring special safeguards164
6.13 Restraint and restrictive practices 166
6.14 Research
6.15 Relationship with the Mental Health
(Care and Treatment) (Scotland) Act 2003 170
6.16 Dispute resolution171
6.17 Confidentiality and information sharing



Introduction

This guidance covers decision making for adults who lack capacity. It does not address compulsory treatment under mental health legislation. The Adults with Incapacity (Scotland) Act 2000 (the Act) sets out the legal framework for decision making on behalf of adults (people aged 16 or over) who cannot make decisions for themselves. It acts alongside the common law power to provide treatment in emergencies to people who are unable to give consent. Amendments to Part 5 of the Act relating to medical treatment and research were introduced in 2005 by section 35 of the Smoking, Health, and Social Care (Scotland) Act.

Part 5 of the Act confers on healthcare professionals a general authority to treat patients under their care who are incapable of consenting to the treatment in question provided a certificate of incapacity is issued for the treatment in question, and provided the general principles of the Act are observed. The common law allows medical treatment to be given in an emergency to patients who cannot consent. There are limits to these powers. For example, a valid decision by an authorised proxy may take precedence and a valid and applicable advance statement refusing treatment is also likely to be binding.

The Act is accompanied by a statutory Code of Practice providing guidance on how it should be used by healthcare professionals. It is therefore essential that healthcare professionals are familiar with this Code of Practice. The website of the Mental Welfare Commission for Scotland provides resources on all aspects of the Act.



Key resources

Adults with Incapacity (Scotland) Act 2000

Mental Welfare Commission for Scotland – Advice and guidance

Scottish Government – Adults with incapacity. Code of Practice for Medical Practitioners



Capacity and incapacity

What is capacity?

Decision making capacity refers to the everyday ability we possess to make decisions or to take actions that influence our lives, from simple decisions about what to have for breakfast, to complex decisions about serious medical treatment. In a legal context it refers to a person's ability to make and execute a decision, which may have legal consequences for themselves or for other people.

When does a person lack capacity?

For the purposes of the Act a person lacks capacity if, at the time a decision needs to be made, they are incapable of acting, making the decision, communicating the decision, understanding the decision, or retaining the memory of the decision due either to a mental disorder or to a physical disability or neurological impairment which prevents communication and which cannot be made good by human or mechanical aid.

The Act therefore contains a two-stage test:

Stage 1 – Is the individual incapable of acting, making decisions, communicating decisions, understanding decisions, or retaining the memory of decisions?

Stage 2 – If so, is that due to either a mental disorder or to a physical disability or neurological impairment which prevents communication and which cannot be made good by human or mechanical aid?

The assessment of incapacity is 'task specific' – it is not an 'all or nothing' concept. The assessment of incapacity must be made in relation to the particular decision that needs to be made, at the time it needs to be made. A central tenet of the Act is that adults must not be labelled as incapable simply because of a specific diagnosis or other circumstance.





Basic principles

What are the Act's basic principles?

The Act contains a set of guiding principles which doctors are legally required to apply to all their interactions with patients with incapacity. Actions or decisions that clearly conflict with these principles are unlikely to be lawful, although there may be occasions where they are in tension, and some balancing will be required. A list of the principles, with brief descriptions, is given below.

Benefit

Any action or decision must be necessary and must be likely to be of benefit to the person. There should be a reasonable expectation that the patient will benefit, and that benefit cannot be achieved without the proposed intervention. If the individual is likely to regain capacity in a reasonable time, and the decision can be delayed without causing harm to the patient, it should be. For more information on benefit see section 6.5.

Least restrictive intervention

Any action or decision taken should be the least restrictive necessary to achieve the purpose. It should be the option that restricts the person's freedom as little as possible.

Take account of the adult's wishes and feelings

In deciding if an action or decision is to be made, and what that should be, account must be taken of the present and past wishes and feelings of the person as far as these may be understood, and to what is known about their beliefs and values as far as they can be ascertained by any means of communication, whether human or by mechanical aid.

Consultation with relevant others

You must take account of the views of others with an interest in the person's welfare. The Act lists those who should be consulted whenever practicable and reasonable. It includes the person's primary carer, nearest relative, attorney or guardian, if there is one - see proxy decision makers in section 6.7. This is not an exhaustive list and the views of others who appear to you to have an interest in the welfare of the adult or the intervention should be considered, so far as reasonable and practicable.



Assessing incapacity

Who should assess incapacity?

The Act does not specify who should assess incapacity where a patient's ability to make a decision has been called into question. However, anyone who wishes to carry out an action in connection with the care or treatment of an individual, or who wishes to make a decision on their behalf, must have a reasonable belief that they lack capacity. In its guidance on *decision making and consent* at paragraph 82 the GMC states:

'Assessing capacity is a core clinical skill and doesn't necessarily require specialist input (e.g. by a psychiatrist). You should be able to draw reasonable conclusions about your patient's capacity during your dialogue with them. You should be alert to signs that patients may lack capacity and must give them all reasonable help and support to make a decision.'

If you believe that the patient may lack the capacity to make a specific decision, then you must assess their capacity to make the decision in question, as set out below. Where consent to medical treatment is required, the healthcare professional proposing the treatment is responsible for ensuring that the patient has the capacity to consent before proceeding.

The reasons why incapacity is suspected should be recorded in the medical record, as should details of the assessment process and its findings. The more serious the decision, the more formal the assessment of incapacity is likely to be.

If there is doubt about whether the patient lacks capacity and is therefore unable to make a specific decision, it can be helpful to seek support from someone who knows the patient well, for example, another member of the healthcare team or someone close to the patient. Although assessing incapacity is a core clinical skill, in complex cases, where you remain unclear as to whether the patient lacks capacity, you should seek specialist input from colleagues such as psychiatrists and psychologists. You should also seek specialist input if the patient or someone close to them disagrees with your judgement.

How do you assess incapacity?

The law of Scotland generally presumes that adults (those aged 16 or over) are legally capable of making decisions, including treatment decisions, for themselves but that presumption can be overturned where there is evidence of impaired capacity.

If doctors receive requests from other healthcare professionals or those in social care to assess capacity, and insufficient information as to the reason for the request is provided, doctors should ask that the relevant information about the person and the decision(s) in question is provided before carrying out the assessment.

When assessing whether an individual lacks capacity to make a particular decision, doctors should ensure, as far as possible, that any factors likely to affect the patient's ability to decide for themselves are addressed beforehand. These may include medication, medical condition, pain, time of day, fatigue, or mood. Any information must be given as clearly and plainly as possible with communication aids used where appropriate. Those assessing a patient's incapacity are also under an obligation to enhance their ability to make decisions as far as reasonably possible. This will involve seeking to



ensure that patients are engaged in decision making when they are best able to participate and are encouraged to participate in decision making to the greatest extent they are able. The Act uses a 'functional' test of capacity. First it must be established that the person is unable to make the decision that needs to be made. Secondly, it needs to be established that this inability to make a decision is the result of a mental disorder (which includes mental illness, learning disability, dementia and acquired brain injury), or severe communication difficulty because of a physical disability or neurological impairment (such as stroke or severe sensory impairment).

Under the Act, a person is regarded as being unable to make a decision if, at the time the decision needs to be made, they are incapable, even with all practicable support, of:

- acting;
- making decisions;
- communicating decisions;
- understanding decisions; or
- retaining the memory of decisions.

When doctors are involved in assessing a patient's capacity to make a decision about treatment, the Code of Practice (see key resources) states that they need to identify whether the patient:

- is capable of making and communicating their choice
- understand the nature of what is being asked and why
- has memory abilities that allow the retention of information
- is aware of any alternatives
- has knowledge of the risks and benefits involved
- $\,-\,$ is aware that such information is of personal relevance to them
- is aware of their right to, and how to, refuse, as well as the consequences of refusal
- has ever expressed their wishes relevant to the issue when greater capacity existed
- is expressing views consistent with previously preferred moral, cultural, family, and experiential background; and
- is not under undue influence from a relative, carer or other third party declaring an interest in the care and treatment of the adult.'

In assessing capacity, family members and close friends may be able to provide valuable background information, although their views about what they might want for the individual must not be allowed to influence the assessment of capacity.

Any decision that a person lacks capacity must be based on a reasonable belief backed by objective reasons. However, difficult judgements will still need to be made, particularly where there is fluctuating capacity, where some capacity is demonstrable but its extent is uncertain, or where impairment may interact with coercion or duress from those close to the individual. More detailed advice on assessing capacity in these circumstances is available from other sources (see key resources).

Where there are disputes about whether a person lacks capacity that cannot be resolved using more informal methods, the Sheriff Court can be asked for a ruling.



What do you do when an individual refuses to be assessed?

Occasionally an individual who is suspected to lack capacity to make a decision may refuse to be assessed. In most cases, a sensitive explanation of the potential consequences of such a refusal, such as the possibility that any decision they may make will be challenged later, will be sufficient for them to agree. However, if the individual flatly refuses, in most cases no one can be required to undergo an assessment. In these circumstances, doctors should document the refusal in the medical record, make a decision about capacity based on the information they have available, and document the decision reached and the reasons for it; where the question of capacity cannot be resolved on the basis of existing information, legal advice should be sought.

If there are reasonable grounds to believe that the refusal of assessment results from coercion or undue influence by a third party, for example if there is a history of abuse, advice should be sought from the local authority under adult support and protection arrangements.



Key resources

General Medical Council – <u>Decision making and consent</u>
Scottish Government – <u>Adults with incapacity (Scotland) Act 2000 Code</u>
of Practice

Scottish Government – <u>Adults with incapacity: guide to assessing capacity</u>



Benefit

What is meant by benefit?

Doctors have a general duty to provide treatment that benefits their patients. There should be a reasonable expectation that the patient will benefit from any proposed intervention and that benefit cannot be achieved without the intervention. Benefit in this context has its ordinary meaning of an advantage or net gain for the patient. It is broader than whether the treatment simply achieves a physiological goal. It includes other less tangible advantages such as respecting the patient's known wishes and values. It also encompasses avoiding harming the individual by infringing their rights. The Supreme Court has said that decision makers must put themselves in the place of the individual patient and ask what their attitude to the treatment is or would be likely to be.

The health care team, proxy decision makers, and people close to the patient should discuss what might benefit the patient, taking into account the patient's past and present wishes. Depending on the powers they have been given, proxies may have the authority to decline treatment if they believe that would benefit the patient, although this decision can be challenged (see section 6.7). In complex cases where the assessment of benefit is difficult or agreement cannot be reached, it may be necessary to take legal advice (see section 6.16).

What should you consider when assessing benefit?

Lacking capacity should not exclude an individual from participating in the decision-making process as far as possible. The decision maker must also consider whether the person will regain capacity. A decision should be delayed if it can reasonably be left until the individual regains the capacity to make it without unduly disadvantaging the patient.

When determining whether an intervention would benefit an adult with incapacity, assumptions must not be made merely on the basis of the individual's age or appearance, their medical condition or any disability, or an aspect of their behaviour — this is the principle of equal consideration and non-discrimination.

In most circumstances it will be clear where the individual's best interests lie, and a decision as to care or treatment will not be challenging or time-consuming – but this is not always the case. Whether to provide analgesics for someone in pain is likely to be a straightforward question; a decision about whether to continue providing life-sustaining treatment is less so. Where a decision is likely to have grave consequences for a person it will require greater consideration, wider consultation with those close to the patient, and more detailed documented evidence about the decision reached and the reasons for it.

Relevant factors to consider are likely to include (so far as they are reasonably ascertainable):

- the person's past and present wishes and feelings, including any relevant written statement made when they had capacity;
- the person's wishes, beliefs, or values where they would have an impact on the decision; and
- other factors the person would have considered if able to do so.



For significant decisions, a crucial part of assessing benefit involves discussion with those close to the individual, including family, friends, or carers, where it is practical or appropriate to do so, bearing in mind the duty of confidentiality (for more on information sharing, see section 6.17). It should also include anyone previously nominated by the person as someone to be consulted. The BMA has a toolkit about how to make decisions for those who lack capacity, including taking account of the individual's wishes, beliefs and values to reach a decision. Although this is based on the legislation in England and Wales, it contains a lot of practical information and guidance that may be helpful for those practising in Scotland (see key resources).

Where there is a proxy with the authority to make treatment decisions on behalf of the individual (see section 6.7), they should be provided with as much information as is necessary for them to make the decision in question.

Can it ever benefit a patient to be given medication covertly?

The Code of Practice for Part 5 of the Act (see key resources) states that the use of covert medication is permissible in certain, limited circumstances, that is to safeguard the health of an adult who is unable to consent to the treatment in question **and** where other alternatives have been explored and none are practicable. Healthcare staff should not give medication except in accordance with the law, and even where the law allows, it should not be given in a disguised form unless the adult has refused, and their health is at risk because of this. Where covert medication is given, healthcare staff are required to record this in the patient's records. Detailed advice and guidance on the use of covert medication has been published by the Mental Welfare Commission – see key resources.

Are there any exceptions to the benefit principle?

There are two circumstances to which the benefit principle may not apply. The first is where someone has previously made a valid and applicable advance statement to refuse treatment while they had capacity, which the Code of Practice says, at paragraph 2.30, is 'potentially binding'. In such circumstances, the advance statement, should normally be respected, even if you or others think that the decision does not benefit the patient. For more information on advance statements see section 6.10. The second exception relates to the enrolment of adults with incapacity in certain forms of research - see section 6.14.



Key resources

British Medical Association – <u>Best Interests decision making for adults</u> who lack capacity. Although this is based on the legislation in England and Wales, the practical information may also be useful for doctors working in Scotland.

Mental Welfare Commission for Scotland – <u>Covert Medication - a legal</u> and practical guide

 ${\bf Scottish\ Government-\underline{Adults\ with\ incapacity.\ Code\ of\ Practice\ for\ \underline{Medical\ Practitioners}}$





Certificate of incapacity and general authority to treat

When should a certificate of incapacity be completed?

Other than in an emergency (see section 6.11), in order to provide medical treatment or care to a patient who lacks capacity the healthcare professional primarily responsible for the patient's care, normally a GP or consultant, must complete a section 47 certificate of incapacity (Certificate).

The Certificate is to state that the patient lacks capacity in relation to a decision about the proposed medical treatment, and authorising treatment that other healthcare professionals will provide (under the instructions of the doctor, or with their agreement). A Certificate is needed to allow healthcare professionals to rely on a proxy's consent to treatment (see section 6.7), or in the absence of a proxy decision maker, to act under the general authority to treat – see below.

What information should the Certificate include?

The Certificate must state:

- that the doctor has examined the patient and is of the opinion that the patient lacks capacity for this particular matter;
- the nature of the medical treatment in question;
- the likely duration of the adult's incapacity; and
- the period for which the specified treatment is authorised.

For routine healthcare needs, multiple treatments can be covered on one Certificate. However, a separate Certificate is required for any intervention that would normally require the signed consent of the adult, such as surgery. A treatment plan may be completed and attached to the Certificate – see below. There is a standard format for the Certificate which must be used. Detailed advice about completing Certificates, with examples, is published by the Scottish Government (see key resources).

How long does a Certificate last?

A Certificate can be issued with a duration of up to one year, but can authorise treatment for up to three years if, in the view of the doctor, no curative treatment is available, and the patient's capacity is unlikely to improve, and the patient has at least one of the following conditions:

- severe or profound learning disability
- severe dementia
- severe neurological disorder.

The doctor should keep the patient's capacity to consent to treatment under review at appropriate intervals during the duration of the Certificate. Where a new Certificate is issued, doctors must consult any proxy decision maker. The guidance from the Scottish government on s 47 Certificate of Capacity states that it is also good practice where reasonable and practicable to discuss it with the patient's nearest relative or carer (see key resources).

When should a new Certificate be completed?

A new Certificate is needed if a new treatment is required that is not covered by the initial Certificate. A new Certificate may also be needed if the patient's condition or diagnosis changes.





When should a treatment plan be completed?

Where there are multiple or complex ongoing healthcare needs the use of a treatment plan is recommended. Certain basic healthcare procedures can be authorised under a single entry on the treatment plan for 'fundamental healthcare procedures' (if the patient is incapable of consenting to any of those procedures). These include nutrition, hydration, hygiene, skin care and integrity, elimination or relief of pain and discomfort, mobility, communication, eyesight, hearing, and oral hygiene. Interventions that fall outside of these fundamental healthcare procedures should be listed separately, with a note made of whether or not the patient is capable or incapable of deciding on each intervention.

As with the Certificate, the treatment plan should be completed by the clinician with overall responsibility for the patient and should be reviewed regularly. Detailed advice on the use of treatment plans is published by the Scottish Government (see key resources).

When can a doctor act under a general authority to treat?

Where there is no proxy decision maker, doctors may issue a Certificate and act under the 'general authority' to treat. This applies to the doctor who has signed the Certificate and members of the healthcare team acting on their behalf. This general authority may not be used where there is a proxy decision maker and it is reasonable for that person's consent to be sought, but this has not been done. Nor can it be used where a pending application has been made to the sheriff for an intervention or guardianship order with powers that cover the medical treatment in question (see section 6.9), or if there is an appeal to the Court of Session regarding treatment. In these cases, only emergency treatment may be provided until the court has ruled.

Can doctors charge a fee for completion of a Certificate of incapacity?

In both primary and secondary care, it is part of doctors' terms and conditions to assess their patients' capacity for medical treatment they are providing. Provision of Certificates in other circumstances and for parts of the Act unrelated to medical treatment may attract a fee.



Key resources

Scottish Government – Section 47 Certificate of Incapacity
Scottish Government – Adults with incapacity: code of practice for medical practitioners, Annex 5 Treatment plan for patients



Proxy decision makers

Who are proxy decision makers?

A proxy decision maker can be a:

- welfare guardian or welfare intervener (appointed by the Sheriff Court see section 6.9), or
- welfare attorney (appointed by the patient under a power of attorney see section 6.8)

GPs who are aware that a patient has a proxy decision maker should note this in the medical record, together with their contact details. Hospitals and other establishments treating patients on an in-patient basis need to make reasonable enquiries to ascertain whether there is a proxy decision maker when a patient is admitted. A register of valid proxies is held by the Office of the Public Guardian and may be checked, including by telephone during office hours. This information might also be available from the patient, their relatives, carers, or others close to the patient. Otherwise, the local authority social work department may be able to help.

What are the responsibilities of a proxy decision maker?

The roles and responsibilities of proxies in relation to medical treatment are set out in the Code of Practice (see key resources). They have a duty of care to the adult on whose behalf they act, and a duty to abide by the general principles set out in the Act (see section 6.3). If it is apparent that a proxy is not fulfilling their duties or is acting contrary to the interests of the patient, this matter should be drawn to the attention of the authorities. Local authorities have a statutory duty to investigate complaints about welfare proxies. Advice is also available from the Public Guardian and Mental Welfare Commission.

What is the role of a proxy decision maker?

When an adult lacks the capacity to make a decision, and a certificate of incapacity has been issued, a proxy who has been granted the relevant power may give consent to medical treatment on behalf of the adult. Where a doctor is aware that a proxy decision maker has been appointed, and it is reasonable and practicable to obtain the proxy's consent for treatment, this must be sought. Wherever possible, doctors should postpone treatment until a proxy has been consulted. In all cases, however, it is important to ensure that discussion with a proxy does not introduce delays that jeopardise the patient's care. Proxies may also refuse medical treatment, if they are fulfilling their duty of care to the adult and are abiding by the general principles in the Act (see section 6.3).

The role of a proxy or other person close to the patient is not to decide what he or she would want in the patient's position. Proxies are under a duty to make decisions that benefit the patient, that are really needed, that are in keeping with the patient's past and present wishes, and that the patient cannot make for themself. This means healthcare professionals need, independently, to have their own view as to what would benefit the patient, so that they can engage with the proxy on an informed basis. If any doubt or disagreement about what would benefit the patient cannot be resolved locally, legal advice should be sought.





If there is disagreement about how to proceed, there are procedures set out in the Act that must be followed - see dispute resolution in section 6.16.

Key resources

Mental Welfare Commission for Scotland
Office of the Public Guardian, Scotland
Scottish Government – Adults with incapacity. Code of Practice for Medical Practitioners





Powers of Attorney

What is a power of attorney?

A power of attorney is a document appointing someone to act and to make decisions on their behalf. The person who grants the power is known as the 'granter' and the person appointed is the 'attorney'. A power of attorney can be useful both for someone anticipating permanent incapacity or to deal with periods of temporary, or fluctuating incapacity.

GPs who are aware that a patient has a welfare power of attorney should note this in the medical record, together with their contact details. Hospitals and other establishments treating patients on an in-patient basis need to make reasonable enquiries to ascertain whether there is a valid welfare power of attorney when a patient is admitted.

Is there more than one type of power of attorney?

Yes. Powers of attorney can deal with financial and/or welfare matters. A welfare power of attorney covers personal, welfare, and healthcare decisions, including decisions relating to medical treatment. Although a power of attorney in relation to property and affairs (a continuing attorney) can be used while the granter still has capacity, a power of attorney dealing with health and welfare can only come into effect at the onset of incapacity. The granter can appoint the same person to deal with financial and welfare matters, or different people.

What are the requirements for making a valid power of attorney?

The following statutory requirements apply to the creation of a power of attorney:

- it must be in a written document;
- the document must be signed by the granter, and state clearly that the powers are continuing, or welfare, or a combination of both;
- it must contain a statement to the effect that the granter has considered how their incapacity should be determined where the authority of the attorney commences on incapacity;
- it must incorporate a certificate in the prescribed form by a practising solicitor, a practising member of the Faculty of Advocates, or a registered and licensed medical practitioner which certifies that they:
 - have interviewed the granter immediately before the granter signed the document;
 - are satisfied, either because of knowledge of the granter or because of consultation with another person who has knowledge of the granter, that at the time of granting the power, the granter understands its nature and extent;
 - have no reason to believe that the granter is acting under undue influence



A power of attorney must be registered with Office of the Public Guardian before it can be used. It does not give the attorney any legal power to make decisions before it is registered or before the individual loses capacity. Whether or not the powers can be exercised will depend on the terms of the power of attorney, and whether the granter has included a clause specifying an event that must happen before the attorney can act, for example an assessment of incapacity by a medical practitioner.



Key resources

Office of the Public Guardian Scotland – <u>What is a power of attorney?</u> Scottish Government – <u>Continuing and welfare attorneys: Code of Practice</u>





Guardianship and intervention orders

What are guardianship and intervention orders?

Guardianship and intervention orders provide legal authority for someone to make decisions and act on behalf of a person who lacks capacity in order to safeguard and promote their interests. The powers granted under an order may relate to the person's money, property, personal welfare, and health.

A guardianship order gives authority for the guardian(s) to act and make certain decisions over the long term. An intervention order is appropriate where there is a need for a 'one-off' decision or action. An application can be made for a financial and/or welfare order depending on the needs of the individual.

An application for a guardianship or intervention order is made to the Sheriff Court. The Sheriff decides if the adult needs a guardian and if the person who wishes to be the guardian is suitable. Once granted, the order is registered with the Office of the Public Guardian and is operational. Doctors who are aware that a patient has a guardianship or intervention order should note this in the medical record, together with their contact details.

What are the limits on the powers of a welfare guardian or intervener?

A guardian or intervener does not have powers to:

- consent to specific treatments regulated under the Adults with Incapacity
 Act (see section 6.12 on treatments requiring special safeguards);
- consent on behalf of the adult to certain medical treatments covered under the Mental Health (Care and Treatment) Act 2003; or
- place an adult in a hospital for the treatment of mental disorder against their will. If the adult resists treatment for a mental disorder, then an application will need to be made by a mental health officer for an order under the Mental Health (Care and Treatment) (Scotland) Act 2003.



Key resources

Office of the Public Guardian Scotland – What is a guardianship order?

Office of the Public Guardian Scotland – What is an intervention order?

Scottish Government – Guardianship and Intervention Orders



Advance statements refusing treatment

Are advance statements refusing treatment legally binding?

Advance statements are not covered by the Act, or case law in Scotland. There is, however, provision in Sections 275 and 276 of the Mental Health (Care and Treatment) (Scotland) Act 2003 which enables a patient to make an advance statement setting out how they would wish to be treated, or not to be treated, should their ability to make decisions about treatment for their mental disorder become significantly impaired as a result of their mental disorder.

Where advance statements are not covered by the provisions of the Mental Health (Care and Treatment (Scotland) Act 2003, paragraph 2.30 of the Code of Practice states:

'A competently made advance statement made orally or in writing to a practitioner, solicitor or other professional person would be a strong indication of a patient's past wishes about medical treatment but should not be viewed in isolation from the surrounding circumstances. The status of an advance statement should be judged in the light of the age of the statement, its relevance to the patient's current healthcare needs, medical progress since the time it was made which might affect the patient's attitude, and the patient's current wishes and feelings. An advance statement cannot bind a practitioner to do anything illegal or unethical. An advance statement which specifically refuses particular treatments or categories of treatment is called an 'advance directive'. Such documents are potentially binding. When the practitioner contemplates overriding such a directive, appropriate legal and ethical guidance should be sought.'

When assessing the validity of an advance statement it is important to remember the general presumption of capacity in Scottish law. Doctors should always start from the assumption that a person who has made an advance statement had the capacity to make it, unless there are reasonable grounds to doubt the person had the capacity to make the statement at the time they made it. In cases of genuine doubt about the existence or validity of an advance statement, doctors can provide treatment that is immediately necessary to stabilise or to prevent a deterioration in the patient's condition until the existence, and the validity and applicability, of the advance statement can be established. If doubts cannot be resolved locally, and time permits, legal advice should be sought about approaching the court for a decision.

Advance requests for future treatment, or statements about matters other than medical treatment, are not legally binding, although they can be a useful indication of a patient's wishes and feelings when making decisions that benefit them.

Are there limits to advance statements refusing treatment?

Although any written or oral statements of patients' future wishes are clearly a vital part of decision making, there are limits to patients' ability to influence their future care. Nobody can authorise or refuse in advance procedures they could not authorise or refuse contemporaneously. They cannot, for example, insist upon treatment that is not clinically indicated. In the BMA's view, it would also be inappropriate for patients to refuse in advance the provision of all forms of 'basic care' such as hygiene and interventions designed solely for the alleviation of pain or distress. This also includes the offer of oral food and water (but not clinically assisted nutrition and hydration).



Is there a specific format for advance statements refusing treatment?

There is no specific form in which an advance statement refusing treatment needs to be made. Oral advance statements can potentially be binding, particularly when supported by appropriate evidence, although a note should be made of any such oral decision in the medical record. It is worth bearing in mind that advance statements can also be recorded, for example on smart phones, although patients have to take appropriate steps to ensure relevant people are made aware of their existence.

Patients wishing to make an advance statement that is likely to have serious consequences for them, including any decision relating to life-sustaining treatment, should ideally put their wishes in writing. In the BMA's view, patients making a written advance statement refusing treatment should include the following:

- full details of the person making the advance decision including their name and address;
- the name and address of the person's GP and whether they hold a copy of the document;
- a statement that the document should be used if the person ever lacks capacity to make treatment decisions;
- a clear statement of the decision, the treatment to be refused, and the circumstances in which the decision will apply;
- the signature of the person making it and any person witnessing the signature; and
- the date the document was written or subsequently reviewed.

It is advisable for patients to review their advance statements regularly, particularly where there are any material changes in the individual's condition or treatment options, and at least every five years.

How should advance statements be stored?

The storage of advance statements, and the obligation to ensure that relevant healthcare professionals are aware of them, are the responsibility of those who make them. A copy of any written advance statement should be given to the patient's GP for storage in the medical record. A copy of the document should be provided to another healthcare professional involved in the patient's care on request. It is good practice for anyone who makes an advance statement to draw it to the attention of anyone who may be called upon to assist in making decisions on their behalf, such as friends, family, or any proxy decision maker. The patient or family members should draw it to the attention of hospital staff before an episode of care.



Key resources

Law Society Scotland – <u>Advance choices</u>, and <u>medical decision making in intensive care situations</u>

Scottish Government – Adults with incapacity, Code of Practice for

Scottish Government – <u>Adults with incapacity. Code of Practice for</u> Medical Practitioners



Treatment in an emergency

Can emergency treatment be provided to adults with incapacity?

It is clearly established under the common law 'principle of necessity' that, in an emergency, where consent cannot be obtained doctors should provide treatment that is immediately necessary either to preserve life or to prevent a serious deterioration in the patient's condition. The only exception to this is where there is clear evidence of a valid and applicable advance statement refusing the treatment in question (see section 6.10).

In some emergency situations a section 47 certificate may be required. Paragraph 2.41 of the Code of Practice gives the following example 'An adult could require lifesaving surgery but there may be a period while they are being rehydrated and given antibiotics before they have an anaesthetic and operation. In this time, the practitioner responsible for the treatment could have time to consult and complete the certificate.' It goes on to say 'The basic judgement as to whether or not there is time to complete the appropriate certificate and undertake the processes associated with its completion is essentially a medical judgement in the first instance. Ultimately, however it will be for the courts to decide whether a practitioner has acted improperly in failing to secure the authority provided by a certificate under section 47 (as amended) of the Act. It is recommended that the authority be used in every case where it is reasonable and practicable to do so.'

Where decisions can reasonably be delayed until such time as the adult is likely to regain capacity, or to permit an assessment of incapacity and discussion with those close to the patient, and any proxy decision maker, then they should be.

What should you do if in an emergency, a patient refuses treatment and there is doubt as to their capacity?

If, in an emergency, a patient refuses treatment and there is doubt about their capacity to do so, doctors should take whatever steps are immediately necessary to preserve life or prevent serious deterioration of the patient's condition and then consider matters of capacity and consent. These steps should also be taken if a proxy refuses to give consent but the doctor in charge judges that treatment would benefit the patient. Once essential treatment has been given, the procedures for resolving disagreement between doctors and proxies must be followed (see section 6.16).



Key resources

Law Society Scotland – <u>Advance choices</u>, and <u>medical decision making in intensive care situations</u>

Scottish Government – <u>Adults with incapacity</u>. <u>Code of Practice for Medical Practitioners</u>



Treatment requiring special safeguards

What treatments require Court approval in Scotland?

There are certain safeguarded treatments that cannot be undertaken on the basis of the general authority to treat, or proxy consent provisions of the Act. These treatments are set out in the Adults with Incapacity (Specified Medical Treatments) (Scotland) Regulations 2002. The following treatments require approval by the Court of Session:

- sterilisation where there is no serious malformation or disease of the reproductive organs;
- surgical implantation of hormones for the purpose of reducing sex drive;
- neurosurgery for mental disorder.

What other treatments may require additional safeguards?

In England, case law (including Supreme Court case law) and Court of Protection guidance have made clear that certain categories of cases are ones where legal advice should be sought to determine whether an application to court is required. Given that these are cases where there is doubt or disagreement about the correct course of action, or where it is considered that the proposed treatment would involve serious interference with the person's human rights, the BMA recommends that doctors in Scotland seek legal advice in cases where:

- at the end of the decision-making process:
 - the decision is finely balanced;
 - there is a difference of medical opinion;
 - there is a doubt or dispute that cannot be resolved locally (see section 6.16) about whether a particular treatment will benefit the patient; or
 - there is a conflict of interest on the part of those involved in the decision-making process;
- the procedure is for the purpose of donation of an organ, bone marrow, stem cells, tissue, or bodily fluid to another person;
- the action proposed involves a procedure for the covert insertion of a contraceptive device or other means of contraception;
- it is proposed that an experimental or innovative treatment be carried out;
 or
- the case involves a significant ethical question in an untested or controversial area of medicine.



What treatments require approval by the Mental Welfare Commission?

The following treatments require approval by a practitioner appointed by the Mental Welfare Commission:

- drug treatment for the purpose of reducing sex drive, other than surgical implantation of hormones;
- electro-convulsive therapy for mental disorder;
- abortion (in addition to meeting the provisions of the Abortion Act 1967);
 and
- any medical treatment which is considered likely by the medical practitioner primarily responsible for that treatment to lead to sterilisation as an unavoidable result.

These requirements do not affect doctors acting in an emergency where treatment is necessary to preserve life or prevent serious deterioration in health (see section 6.11).



Key resources

Law Society Scotland – <u>Advance choices</u>, and <u>medical decision making</u> in intensive care situations



Restraint and restrictive practices

What is restraint?

There may be occasions when healthcare professionals need to consider the use of restraint in treating an individual lacking capacity. Restraint is the use or threat of force, to make someone do something they are resisting, or restricting a person's freedom of movement, whether they are resisting or not. Section 47(7)(a) of the Act states that the use of force or detention is not authorised, 'unless it is immediately necessary and only for so long as is necessary in the circumstances'. Healthcare professionals therefore have the right to use proportionate restraint to prevent the immediate risk of harm to the patient or others.

Where relevant, any use of restrictive practices, including the use of restraint, should comply with the Regulation of Care (Requirements as to Care Services) (Scotland) Regulations 2002 (the Regulations), and the Mental Welfare Commission's guidance on rights, risks, and limits to freedom (see key resources).

What are the types of restraint?

Restraint can be overt, such as the use of bed rails. It can also be covert and indirect such as having doors that are heavy and difficult to open or putting patients in low chairs from which they find it difficult to move. The Mental Welfare Commission in its guidance states '…restraint is taking place when the planned or unplanned, conscious or unconscious actions of care staff prevent a resident or patient from doing what he or she wishes to do and as a result is placing limits on his or her freedom'. The National Care Standards define restraint as 'Control to prevent a person from harming themselves or other people by the use of:

- physical means (actual or threatened laying of hands on a person to stop them carrying out a particular action);
- mechanical means (for example, wrapping someone in a sleeping bag or strapping them to a chair);
- environmental means (for example, using cot sides to prevent someone getting out of bed); or
- medication (using sedative or tranquillising drugs for the symptomatic treatment of restlessness or agitated behaviour)'.

When is restraint lawful?

Restrictive measures should be a last resort and alternatives to restraint must always be considered. Anybody proposing to use restraint must have objective reasons to justify that it is necessary. They must also be able to show that the patient is likely to suffer harm unless proportionate restraint is used. A proportionate response means using the least intrusive type and the minimum amount of restraint for the smallest amount of time to achieve the objective, to the benefit of the patient. The use of restraint must also be proportionate to the likelihood and seriousness of harm. If these conditions are met, it is permissible to restrain a patient to provide necessary treatment. It also follows that in such circumstances there would be no liability for assault.



Where a healthcare professional working in a registered care service is using restraint, either as a direct intervention or a safety measure, the Regulations provide that they must undertake a comprehensive risk-benefit assessment and document the outcomes and actions. Any actions should make clear that they are the only practicable means of securing welfare and detail the exceptional circumstances.

The Regulations also state that where restraint or control has been used, details of the form of restraint or control, the reason why it was necessary and the name of the person authorising it must be documented.



Key resources

Mental Welfare Commission for Scotland – <u>Rights, Risks and limits to</u> freedom

<u>The Regulation of Care (Requirements as to Care Services) (Scotland)</u>
<u>Regulations 2002</u>



Research

Can patients who lack capacity participate in research?

Yes. Under the Act, adults who lack the capacity to consent can be enrolled in research provided the following conditions are met:

- the research will provide a direct benefit to the adult with incapacity
 or, exceptionally, where the research is likely to improve scientific
 understanding of the adult's condition and contribute to the attainment
 of real and direct benefit to persons suffering from the same form of
 incapacity;
- the research cannot be undertaken involving adults with the capacity to consent to it. This condition is binding – it is not sufficient to say that it has not been possible to identify participants with capacity;
- the research presents little or no foreseeable risk or discomfort to the adult with incapacity;
- the adult does not object to involvement in the research;
- consent has been obtained from a person with authority to provide it, such as a guardian or welfare attorney. If no such person exists, consent must be sought from the person's nearest relative; and
- the research has been approved by the Ethics Committee established in Scotland for that purpose (see key resources).

These conditions, which are in no order of priority must all be met before the research can proceed.

More information about research can be found in the Adults with Incapacity Code of Practice (see key resources).

Can adults with incapacity participate in 'emergency' research?

'Emergency' research other than clinical trials of investigational medical products (see below) requires consent. It follows therefore that the inclusion of adults who cannot consent for themselves in research other than clinical trials requires consent from either a welfare attorney, welfare guardian or, if neither are appointed, the adult's nearest relative.

In December 2006, an amendment to the 2004 Clinical Trials Regulations introduced provisions enabling patients to be enrolled in clinical trials of pharmaceutical products without prior consent in emergency situations where the research is approved by an appropriate research ethics committee.

Given the potential vulnerability of adults with incapacity who are enrolled in research, it is important that doctors undertaking such research are familiar with the substantial body of guidance reflecting international standards for research involving adults who lack capacity.



Can doctors provide innovative treatment to patients lacking the capacity to consent to it?

Doctors have always modified methods of investigation and treatment in light of experience and so innovative therapy is a standard feature of good care. There are occasions however where innovative treatment may involve exposing patients to significant risk. Where adults lack the capacity to consent to innovative treatment, any such treatment must be governed by the Act, in particular it must benefit the person. Where any proposed treatment differs significantly from existing practice and involves unknown or significant risk, considerable care must be taken as innovation can give rise to legal and ethical uncertainty. In these circumstances, it is advisable to seek both expert clinical scrutiny and legal advice.



Key resources

The Adults with Incapacity (Ethics Committee) (Scotland) Regulations 2002

Scottish Government – <u>Adults with incapacity. Code of Practice for Medical Practitioners</u>





Relationship with the Mental Health (Care and Treatment) (Scotland) Act 2003

What happens where treatment may be possible under both mental health and mental capacity legislation?

This guidance covers decision making for adults who lack capacity. It does not address compulsory treatment under mental health legislation. However, questions will sometimes arise as to whether it is appropriate to provide treatment to a patient using mental capacity or mental health legislation.

This is a complex area of law and in cases of uncertainty, advice should be sought from the Mental Welfare Commission. As a general rule, if the patient retains capacity with regard to the treatment or intervention, mental capacity legislation cannot be used. Where the treatment is for a physical condition unrelated to the patient's mental disorder, mental health legislation cannot be used.

Where a patient who lacks capacity's physical disorder arises as a 'consequence' of their mental disorder, it is possible that treatment can be provided under either mental capacity or mental health legislation. In relation to the choice as to which legislative framework to use in these circumstances, the Mental Welfare Commission advises that where there is resistance or objection to treatment, either for a mental disorder or for a physical disorder that is a consequence of the mental disorder, mental health legislation should be used. In the absence of resistance or objection from the patient, mental capacity legislation can be used, provided the patient meets the relevant criteria.



Key resources

Mental Welfare Commission – <u>Right to treat? Delivering physical</u> healthcare to people who lack capacity and refuse or resist treatment



Dispute resolution

When can disputes occur?

There may be occasions in relation to the care and treatment of a person who may lack capacity where disagreements with the proxy decision maker, or others close to the patient arise. These may relate to:

- whether an individual retains the capacity to make a decision;
- whether a proposed decision or intervention will benefit a person with incapacity; or
- whether the decision or the intervention is the most suitable of the available options.

It is clearly in everybody's interests that disagreements are resolved as soon as possible, and with as much consensus as possible. Broadly speaking, disputes can be resolved either informally or formally. Some disputes will be so serious that it may be necessary to make an application to court.

How should a dispute be approached initially?

Many disputes can either be avoided, or settled rapidly, by using good communication and involving all relevant individuals. Where healthcare professionals are involved in a dispute with those close to a person who lacks capacity, it is a good idea to:

- set out the different options in a way that can be clearly understood;
- invite a colleague to talk the matter over and offer a second opinion;
- consider enrolling the services of an advocate; and
- arrange a meeting to discuss the matter in detail.

When should mediation be considered?

Where the methods outlined above do not successfully resolve the dispute, it may be a good idea to involve a mediator. Any dispute that is likely to be settled by negotiation is probably suitable for mediation. A mediator is an independent facilitator. It is not the role of a mediator to make decisions or to impose solutions. The mediator will seek to facilitate a decision that is acceptable to all parties in the dispute.

What happens if the dispute cannot be resolved informally?

Where the doctor who signed the Certificate of incapacity (see section 6.6) and a proxy disagree about a treatment (or non-treatment) decision, the doctor can obtain a second opinion from a medical practitioner nominated by the Mental Welfare Commission. The nominated medical practitioner must consult the proxy. He or she must also consult anybody else nominated by the proxy (so far as is reasonable and practicable). If the nominated medical practitioner agrees with the treating doctor, the treatment may be given notwithstanding the proxy's refusal, unless the proxy makes an application to the Court of Session. If the nominated medical practitioner disagrees with the treating doctor, legal advice should be sought.



What role does the court have?

Appeal to the court should be very rare. In all cases of disagreement that cannot be resolved, doctors should seek legal advice. All decisions about medical treatment, under the general authority to treat, or where there is a proxy, are open to appeal to the courts. Any person with an interest in the personal welfare of an adult with incapacity may challenge a decision by appealing to the Sheriff and then, by leave of the Sheriff, to the Court of Session. This person may be the treating doctor, another member of the clinical team caring for the adult, a proxy decision maker, or a close relation or person who has lived with, and cared for, the adult over a significant period. It does not include 'onlookers' such as interested pressure groups, uninvolved neighbours or those seeking to achieve objectives which are of wider significance than the welfare of the particular adult. While an appeal is pending, doctors may provide only emergency treatment (see section 6.11).

The courts can instruct that the patient should receive the treatment in question but cannot instruct a particular doctor to provide treatment contrary to their professional judgement or conscience.

Going to court can be distressing for those concerned. However, the benefits are that a court can give rulings very quickly when necessary, and it can provide a protective role for both patients and the healthcare team in cases where there is a disagreement that cannot be resolved.

What if a complaint is made?

It may be that as part of the dispute resolution process, those acting on behalf of an adult with incapacity might wish to lodge a complaint about the services they have received. Healthcare professionals should be able to provide information about the formal NHS complaints process.



Confidentiality and information sharing

Is a duty of confidentiality owed to patients who lack capacity?

Yes. Healthcare professionals owe the same duty of confidentiality to all their patients whether or not they lack capacity. Healthcare professionals may therefore usually only disclose information where it will benefit the patient.

What is the role of welfare attorneys, and proxy decision makers?

Welfare attorneys and other proxy decision makers whose authority extends to medical decisions have the right to give or withhold consent to treatment and so must be involved in treatment decisions, although where emergency treatment is required, this may not always be possible or practicable.

The healthcare team must provide the proxy decision maker with all the relevant information including the risks, benefits, side effects, likelihood of success and level of anticipated improvement if treatment is to be given, the likely outcome if treatment is withheld and any alternatives that might be considered. While it will therefore be necessary for proxy decision makers to have information that will enable them to act or make decisions on behalf of the patient, it does not mean that they will always need to have access to all the patient's records. Only information relevant to the issue in question should be disclosed.

What role do relatives, carers and friends have?

If a patient lacks capacity, healthcare professionals may need to share information with relatives, friends, or carers to enable them to provide information to help assess whether the proposed intervention will benefit the patient. 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. Where the information is particularly sensitive, for example sexual health, 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.

Is there a role for 'next of kin'?

Despite the widespread use of the phrase 'next of kin' this is neither defined, nor does it have formal legal status in relation to decision making about medical treatment. A 'next of kin' has no rights of access to a patient's medical records or to information on a patient's medical condition. On the other hand, if, prior to losing capacity, a patient nominates an individual and gives authority for their condition to be discussed with them, they can provide valuable information.

There are no rules about who can and cannot be nominated as someone to be consulted. A patient may nominate their spouse, partner, member of their family or friend. In the absence of a named individual, the healthcare team should consult with people who are close to the patient; depending on the seriousness and implications of the decisions to be made, this may be a group of people rather than one individual.



When should disclosures be made to protect adults who lack capacity?

In the absence of a legal requirement, where adults lack the capacity to make a decision about whether or not to disclose information relating to harm or abuse, decisions need to be made on their behalf. Healthcare professionals can make a decision based upon an assessment of what would benefit the individual. When considering a disclosure of information, any assessment of benefit will ordinarily involve discussion with those close to the individual. However, care must be taken to ensure that anyone consulted who is close to the individual is in fact acting in the person's interests. Healthcare professionals must disclose information to the appropriate authority where there is a belief that an adult lacking capacity is at risk of abuse or other serious harm, unless it is not in the overall benefit of the patient to do so.



Key resources

BMA – <u>Confidentiality and health records toolkit</u>
Mental Welfare Commission for Scotland – <u>Good Practice Guide Carers</u>
and <u>Confidentiality</u>



7

Children and young people



Contents

7.1 Introduction and basic principles	. 1//
7.2 Assessing competence	. 178
7.3 Parental responsibility	. 179
7.4 Consent and refusal	. 182
7.5 Best interests	<u>. 184</u>
7.6 Unaccompanied minors	. 185
7.7 16 or 17-year-olds who lack capacity	. 187
7.8 Disputes	. 189
7.9 Use of restraint when providing treatment	. 191
7.10 Confidentiality	. 193
7.11 Vaccination	. 196
7.12 Sexual activity	. 197
7.13 Sexual activity – additional obligations	400
in Northern Ireland	<u>. 199</u>
7.14 Child protection	200
7.15 Female genital mutilation	201
7.16 Compulsory treatment for a mental health condition	202
7.17 Research and innovative treatment	204



Introduction and basic principles

Questions about children and young people make up a significant area of ethical enquiry for the BMA. High-profile cases around disagreements as to what is in a child's best interests, child protection, access to sexual health services, trans healthcare, and the vaccination of children highlight the sensitivity and difficulties doctors face in this area. Doctors need to know when a young person is competent and what this means in terms of their ability to consent and refuse healthcare, and what limits are placed on those with parental responsibility.

This guidance has sections about specific areas relating to the examination and treatment of people in England, Wales, and Northern Ireland who are aged under 18, and in Scotland under 16. There are separate sections identifying factors to be considered when assessing competence and determining 'best interests', and sensitive areas including child protection and access to sexual health services.

Basic principles have been established regarding the way the treatment of children and young people should be approached. These reflect standards of good practice, which are underpinned by domestic and international law.

The welfare of children and young people is the paramount consideration in decisions about their care. Children and young people can expect:

- to be kept as fully informed as they wish, and as is possible, about their care and treatment;
- healthcare professionals to act as their advocates;
- to have their views and wishes sought and considered as part of promoting their welfare in the widest sense;
- to be the individual who consents to treatment when they are competent, and wish to do so;
- to be encouraged to take decisions in collaboration with other family members, especially parents, if this is feasible; and
- that information provided will remain confidential unless there are exceptional reasons that require confidentiality to be breached.

Doctors caring for children and young people have a number of ethical and legal obligations with which they should be familiar and that are outlined in best practice guidance, statute, and case law. For example, the Gillick case, Children Acts 1989 and 2004, the Children (Scotland) Act 1995, Children (Northern Ireland) Order 1995, Age of Legal Capacity (Scotland) Act 1991, Family Law Reform Act 1969, Human Rights Act 1998, and the United Nations Convention on the Rights of the Child.



Key resources

GMC – 0-18 years: guidance for all doctors
Royal College of Paediatrics and Child Health and partnership
organisations – Supporting LGBTQ+ children and young people –
principle statement



Assessing competence

Can competence ever be presumed?

Yes. All people aged 16 and over are presumed in law to be competent to give their consent to medical treatment in England, Scotland, Wales, and Northern Ireland (see section 7.7 for more information on 16 or 17-year-olds who lack mental capacity).

Can a young person be competent under the age of 16?

Yes, but this needs to be assessed in each case on an ongoing basis. Doctors should aim to involve all children and young people in decisions relating to their medical treatment. It is important to recognise when a young person can make a valid choice about a proposed medical intervention or disclosure of personal medical data and is therefore competent to make a personal decision. Doctors should not judge the ability of a particular child or young person solely based on their age.

For a young person under the age of 16 to be competent, they should have:

- the ability to understand that there is a choice and that choices have consequences;
- the ability to weigh the information and arrive at a decision;
- a willingness to make a choice (including the choice that someone else should make the decision);
- an understanding of the nature and purpose of the proposed intervention;
- an understanding of the proposed intervention's risks and side effects;
- an understanding of the alternatives to the proposed intervention, and the risks attached to them; and
- freedom from undue pressure.

Competent under 16-year-olds are sometimes referred to as being 'Gillick competent'. In England, Wales, and Northern Ireland, children aged 12 or over are generally expected to have the competence to give or withhold their consent to the release of information. In Scotland, anyone aged 12 or over is legally presumed to have such competence (see section 7.10 on confidentiality).

Who should assess competence?

Healthcare professionals who assess competence need to be skilled and experienced in discussions with young patients and eliciting their views. The treating doctor may be the most appropriate person, but other members of the healthcare team who have a close rapport with the patient may also have valuable contributions to make. The healthcare professional providing the treatment must be satisfied that the patient is competent before providing the treatment if they are relying on their consent.

How can competence be promoted?

When assessing a child's competence, it is important to explain the issues in a way that is suitable for their age. A young patient may be competent to make some, but not all, decisions and clinical staff should promote an environment in which young patients can engage in decisions as much as they are able. The child or young person's ability to play a full part in decision making can be enhanced by allowing time for discussion.



Key resources

GMC – 0-18 years: guidance for all doctors



Parental responsibility

Who can consent on behalf of a baby or child who lacks competence?

Someone with parental responsibility, provided the decision is in the best interests of the child.

Do all parents have parental responsibility?

No. Not all parents have parental responsibility. In the UK, a mother automatically acquires parental responsibility at birth.

A father acquires parental responsibility if he is married to the mother at the time of the child's birth (conception in Scotland) or subsequently. An unmarried father will acquire parental responsibility if he is recorded on the child's birth certificate (at registration or upon re-registration).

For births registered outside the UK, the rules for the country where the child resides apply.

Can other people have parental responsibility?

An unmarried father who is not recorded on the child's birth certificate, does not have parental responsibility even if he has lived with the mother for a long time. However, the father can acquire parental responsibility by way of a court registered parental responsibility agreement with the mother or by obtaining a parental responsibility order or a residence order from the courts. Married step-parents and registered civil partners can acquire parental responsibility in the same ways. Parental responsibility awarded by a court can only be removed by a court.

For a child born under a surrogacy arrangement, parental responsibility will lie with the surrogate mother if she is married, or in a civil partnership and her husband or partner until the intended parents either obtain a parental order from a court under the Human Fertilisation and Embryology Act 1990, or adopt the child.

Where the surrogate mother is not married or in a civil partnership, the intended mother or non-biological intended father in the surrogacy arrangement will have parental responsibility jointly with the surrogate mother provided:

- they were treated together in a UK clinic that is licensed by the Human Fertilisation Embryology Authority (HFEA);
- they both signed the relevant form provided by the clinic, before the child's conception; and
- they are both named on the birth certificate.

Other people can also acquire parental responsibility for a child including:

- a guardian named in a will if no one with parental responsibility survives the person who wrote the will;
- a guardian appointed by a court;
- the adoptive parents when a child is adopted; and
- a local authority, shared with anyone else with parental responsibility, while the child is subject to a care or supervision order (foster parents rarely have parental responsibility).

Parents are also entitled to authorise another person to take over particular responsibilities. For example, a parent may consent for another person to take the child for a vaccination, or to collect medication.



What if the parents are divorced?

Parents do not lose parental responsibility if they divorce, nor can a separated or divorced parent relinquish parental responsibility. This is true even if the parent without custody does not have contact with the child and does not make any financial contribution.

Until what age can parental responsibility be exercised?

In England, Wales, and Northern Ireland, parental responsibilities may be exercised until a young person reaches 18 years. In Scotland, only the aspect of parental responsibilities concerned with the giving of 'guidance' endures until 18 years – guidance meaning the provision of advice. The rest is lost when the young person reaches 16 years, although some may be lost before this if the child attains the legal capacity to act on their own behalf.

What is the role of parents who do not have parental responsibility?

It should be noted that parents who do not have parental responsibility may also play an essential role in determining best interests and may have a right, under the Human Rights Act, to participate in treatment decisions.

Are there any limits to what people with parental responsibility can consent to?

The moral authority behind parental responsibility depends on the entirely reasonable supposition that parents will act in the best interests of their children. If it appears, however, that parents are following a course of action which is contrary to their child's interests, their decisions can be challenged. Where doctors believe that parental decisions are not in the best interests of the child, it may be necessary to seek a view from the courts, whilst providing only emergency treatment that is essential to preserve life or prevent serious deterioration.

What happens if there is a disagreement between people with parental responsibility?

Generally, the law requires doctors to have consent from only one person to lawfully provide treatment. In practice, however, parents sometimes disagree, and doctors are reluctant to override a parent's strongly held views, particularly when it is not clear what is best for the child. Discussions aimed at reaching a consensus should be attempted. If this fails, a decision must be made by the clinician in charge whether to go ahead despite the disagreement. The onus is then on the parent who refuses treatment to take steps to stop it. There are a small number of procedures (including non-therapeutic male circumcision - see key resources - or vaccination (see section 7.11) where, when it is known that one parent objects, doctors must not proceed without the authority of a court (see section 7.8 on disputes). These are often irreversible, elective and/or controversial procedures.

What if the parents are not communicating with each other?

There are occasions when parents do not communicate with each other, but both want to be involved in their child's healthcare. For example, GPs are frequently asked to tell the parent with whom the child is not resident when the other parent brings the child to the surgery. There is no requirement for GPs to agree to such requests, which could entail a lot of time and resources if the child presents frequently. It is clearly better if parents can communicate with each other about their child's health, although doctors may agree to contact the absent parent under certain circumstances, for example if there is a serious concern.



Where a procedure is controversial, for example, non-therapeutic male circumcision, if a child presents with only one parent the doctor must contact the other parent to seek consent.



Key resources

BMA – Non-therapeutic male circumcision (NTMC) of children – practical guidance for doctors



Consent and refusal

Who can consent to a child or young person's treatment?

The following are legally entitled to give consent to medical treatment of a child or young person:

- a competent child or young person (see section 7.2 on assessing competence);
- a parent or other person or agency with parental responsibility where the
 decision is in the best interests of the child (see sections 7.3 and 7.5 on
 parental responsibility and best interests);
- a court;
- in Scotland, an appointed proxy where patients are aged 16 or over and unable to make decisions themselves (see section 7.7 on 16 or 17-yearolds who lack mental capacity); and
- a person caring for a child, for example, a grandparent or childminder, may do what is reasonable in the circumstances to safeguard or promote the child's welfare (see section 7.3 on parental responsibility). In Scotland, the primacy of any known wishes of the parents in these situations has statutory force. If a carer brings a child for treatment, steps should be taken to ascertain the parents' views, and if there is doubt about authority to proceed, doctors should seek legal advice.

Are there any procedures a young person aged 16 or over is not presumed to be competent to consent to?

In England, Wales and Northern Ireland there are some rare procedures, for example live organ donation, some non-therapeutic procedures and research, where the presumption of competence for 16 or 17-year-olds does not apply. In these circumstances a 16 or 17-year-old is only considered competent if Gillick competent (see section 7.2 on assessing competence). These exceptions do not apply in Scotland where a young person is treated as an adult from the age of 16.

If a competent young person can consent to treatment, does it also follow that they can refuse treatment?

No, not always. In England, Wales, and Northern Ireland, a competent refusal by a patient under 18 can be overruled by a court or by a person with parental responsibility. Healthcare professionals faced with an informed refusal of a treatment they believe to be in the patient's best interests should take legal advice, for example, a refusal of lifesaving treatment or treatment that would prevent permanent injury. The reasons why the child or young person has refused should be discussed beforehand to ensure the refusal is not based on inaccurate perceptions. In Scotland, it seems likely from current case law and statute that a competent refusal cannot be overridden by any other person, carer, or court, even if that treatment is necessary to save or prolong life. This matter is not beyond doubt and legal advice should be sought when such situations arise.

The same principles apply to advance decisions to refuse treatment. In UK jurisdictions where a young person's contemporaneous refusal of treatment may not be determinative, it follows that advance decisions to refuse treatment made by young people cannot be legally binding on healthcare professionals.



However, before seeking consent from either a person with parental responsibility or a court, doctors must look at whether the harms associated with imposing treatment on a patient who refuses, competently or not, outweigh the potential benefits, how critical the treatment is, whether alternative less invasive treatments are available, and whether it is possible to allow time for further discussion with the patient. As much time as is practicable should be taken for discussion, and treatment delayed if that is possible without jeopardising its likely success.

Can a person with parental responsibility refuse treatment?

Refusal by those with parental responsibility is not necessarily determinative if treatment is considered in the child or young person's best interests, a competent young person consents to treatment, or the court approves treatment. For example, where children need blood products to prevent death or serious deterioration, a refusal by a parent who is a Jehovah's Witness is unlikely to be binding on doctors.

In an emergency, where consent is unavailable, on what basis can a child or young person be treated?

In an emergency, where consent is unavailable, for example, when the patient is unable to communicate their wishes and where nobody with parental responsibility is available, it is legally and ethically appropriate for healthcare professionals to proceed with the treatment necessary to preserve the life, health, or wellbeing of the patient. An emergency is best described as a situation where the requirement for treatment is so pressing that there is no time to refer the matter to court.

If such an emergency involves administering a treatment to which the child and/or family is known to object, for example, the administration of blood to a Jehovah's Witness, viable alternatives should be explored if time allows. In extreme situations, however, healthcare professionals are advised to take all essential steps to stabilise the patient. Legal advice may be needed once emergency action has been taken.



Key resources

GMC – <u>0-18 years: guidance for all doctors</u>



Best interests

Who decides what is in a child or young person's 'best interests'?

Where a child lacks competence there is a presumption that the child's parents have the child's best interests at heart. This is not always the case, however, and doctors should be alert to situations in which parents' decisions appear to be contrary to their child's interests.

Where a young person is competent, the young person's views on what would be in their best interests are of importance to the decision-making process, although they may not always be determinative.

What needs to be considered when assessing a child's or young person's best interests?

A best interests judgement is as objective a test as possible of what would be in the child's actual best interests, considering all relevant factors. It is customary to assume that a person's interests are usually best served by measures that offer the hope of prolonging life or preventing damage to health, but this is not always the case. Several factors should be considered, including:

- the patient's wishes, feelings, and values (where these can be ascertained);
- the patient's ability to understand what is proposed and weigh up the alternatives;
- the patient's potential to participate more in the decision, if provided with additional support or explanations;
- the patient's physical and emotional needs;
- clinical judgement about the effectiveness of the proposed treatment, and particularly other options;
- where there is more than one option, which option is least restrictive of the patient's future choices;
- the likelihood and extent of any improvement in the patient's condition if treatment is provided;
- risks and side effects of the treatment or non-treatment;
- the views of parents and others who are close to the patient about what is likely to benefit the patient;
- relevant information about the patient's religious or cultural background;
 and
- the views of other healthcare professionals involved in providing care to the child or young person, and of any other professionals who have an interest in their welfare.

What if there is disagreement over what is in a child or young person's best interests?

Where there is disagreement over what is in the best interests of a child or young person, further discussion should take place and a second opinion should be offered, but it may be necessary to seek mediation, the views of a Clinical Ethics Committee (CEC), and/or legal advice. In the interim, only emergency treatment that is essential to preserve life or prevent serious deterioration should be provided (see sections 7.3 and 7.8 on parental responsibility and disputes).



Key resources

GMC – <u>0-18 years: guidance for all doctors</u>



Unaccompanied minors

Can children or young people make appointments for themselves?

Healthcare staff should not prohibit children and young people from making appointments and seeing a doctor without an accompanying adult. Although there are circumstances in which it is reasonable for doctors to want a parent present, for example, because the child has a serious condition and needs help in complying with a treatment regime, a rule prohibiting young patients attending alone is not good practice and could lead to a complaint against the doctor. Establishing a trusting relationship between the patient and doctor at this stage will do more to promote health than if doctors refuse to see young patients without involving their parents.

Some doctors may be anxious about seeing young patients, especially in very sensitive or complex situations, without any input from an appropriate adult. The possible provision of family or parental support in these circumstances needs to be at least raised in the consultation, even though patients may reject the notion for various reasons, and their views then need to be respected.

Is there a minimum age for consultations?

There is no reason why a patient of any age who is competent to make a request should not be able to ask to see a doctor in private. Doctors too may want to ask to see a patient alone. If, for example, a doctor suspects that a child is experiencing any form of child abuse, neglect or bullying, it may be appropriate to talk to the child privately (see section 7.14 on child protection).

What if a child or young person fails to collect test results?

Where possible, healthcare professionals should arrange in advance how competent children and young people will collect test results, and what should happen if they fail to collect them. If a prior arrangement has not been agreed, doctors should examine all reasonable options, including writing to or telephoning the patient, with due regard to confidentiality. If the young person lives with their parents and does not want the parents to know of the health interaction this should be borne in mind when considering the best way of contacting the patient.

Should a chaperone always be offered when a child or young person is unaccompanied?

The presence of a chaperone can sometimes deter young people from being frank and from asking for help, but as with adult patients, whether or not a chaperone is offered will depend on the nature of the consultation. GMC guidance (see key resources) states that when an intimate examination is being carried out a chaperone should be offered wherever possible, and this person should usually be a health professional.

When no chaperone is available, and either the doctor or the patient does not wish the examination to proceed without a chaperone present, or if either is uncomfortable with the choice of chaperone, the doctor may offer to delay the examination to a later date when a chaperone (or an alternative chaperone) will be available, if this is compatible with the patient's best interests. If the patient does not want a chaperone, and the examination cannot be delayed, the doctor should record that the offer was made and declined.



Further guidance on the use of chaperones can be found in the <u>BMA's doctor-patient relationship toolkit.</u>

Key resources

 ${\sf GMC-} \\ \underline{\sf Intimate\ examinations\ and\ chaperones}$

GMC – <u>0-18 years: guidance for all doctors</u>



16 or 17-year-olds who lack mental capacity

There may be occasions when a 16 or 17-year-old, who would usually be presumed to be competent to make decisions, may lack capacity. In these circumstances, doctors are advised to look at more detailed guidance on mental capacity and they may need to seek expert advice (see key resources).

On what basis can decisions be made for 16 and 17-year-olds who lack capacity in England and Wales?

In England and Wales, most of the Mental Capacity Act 2005 (MCA) applies to 16 and 17-year-olds who lack capacity because of an impairment of, or a disturbance in the functioning of, the mind or brain. At the heart of the Act is the principle that any decision or action taken must be in the best interests of the 16 or 17-year-old who lacks capacity. The BMA has separate guidance on mental capacity (see key resources).

There are some provisions relating to healthcare in the Act that do not apply to 16 and 17-year-olds, namely they cannot make a legally binding Lasting Power of Attorney (LPA) or advance decision to refuse medical treatment (ADRT).

Where the MCA applies, there is no need to obtain consent from anyone, as the legislation provides a workaround for the fact that the young person cannot give consent. Those who are important in the young person's life, however, particularly those with parental responsibility, should be consulted as part of the best interests decision-making process.

Separately, and in parallel, those with parental responsibility have the ability to consent on behalf of a young person under the age of 18 where such consent is within the scope of their parental responsibility, and they are acting in the young person's best interests. In practical terms, healthcare professionals and those with parental responsibility should try to reach agreement about what would be in the young person's best interests. Where agreement cannot be reached, the process set out in section 7.8 for resolving dispute should be followed.

On what basis can decisions be made for 16 and 17-year-olds who lack capacity in Scotland?

In Scotland, the Adults with Incapacity (Scotland) Act 2000 sets out the framework for regulating interventions in the affairs of adults (people aged 16 and over) who have impaired capacity. It allows people aged 16 and over who have the capacity to appoint a welfare attorney to make health and personal welfare decisions once capacity is lost. The Court of Session may also appoint a deputy to make these decisions. The BMA has separate guidance on adults with incapacity (see key resources).

In Scotland, those with parental responsibility cannot give consent on behalf of a 16 or 17-year-old; only those aspects of parental responsibility concerned with the giving of 'guidance' endures until the young person reaches 18 years old.



On what basis can decisions be made for 16 or 17-year-olds who lack capacity in Northern Ireland?

In Northern Ireland, the Mental Capacity Act (Northern Ireland) 2016 was enacted by the Northern Ireland Assembly in May 2016, but currently only the sections relating to research, money and valuables, and to deprivation of liberty are in force. Apart from these provisions, the care and treatment of individuals aged 16 and over who lack capacity in Northern Ireland remains largely governed by the common law (or, in some cases, the Mental Health (Northern Ireland) Order 1986), with serious interventions potentially requiring High Court Declaratory Orders.

Under the common law, all decisions taken on behalf of 16 or 17-year-olds who lack capacity in Northern Ireland must be taken in their best interests. The BMA has separate guidance on mental capacity in Northern Ireland (see key resources)

In addition, in Northern Ireland, people with parental responsibility (see section 7.3) can give consent for procedures that are in the young person's best interests. In practical terms, healthcare professionals and those with parental responsibility should try to reach agreement about what would be in the young person's best interests. Where agreement cannot be reached, the process set out in section 7.8 for resolving disputes should be followed.



Key resources

BMA - Mental Capacity Act toolkit

BMA – Adults with incapacity in Scotland toolkit

BMA – Mental capacity in Northern Ireland toolkit



Disputes

When do disputes occur?

Ideally, medical decisions are made in partnership between the patient, the family, and the healthcare team, with the parental role gradually reducing as the child develops in maturity. Disputes arise, however, where there is a difference of opinion as to what is in a child's or young person's best interests. For example, there could be a disagreement between a competent young person and their parents, the parents may disagree with each other, or the family may oppose the treatment plan suggested by the healthcare team. See, for example, a summary of the case of Yates & Gard v Great Ormond Street Hospital for Children NHS Foundation Trust & Anor (2017).

How should a dispute be approached?

Many disputes arise because of poor communication and all efforts should be made to avoid this. An independent second opinion, the view of a clinical ethics committee (CEC) and/or mediation may help to resolve some disagreements, but ultimately some may have to be resolved by the courts. Healthcare professionals must always focus on the overall best interests of the child or young person.

When should legal advice be sought?

Legal advice should be sought swiftly when:

- agreement over how to proceed cannot be reached (for example where consent is refused by the holders of parental responsibility);
- a competent young person refuses an intervention or invasive treatment that the healthcare team considers necessary;
- administering treatment against the wishes of a competent young person would require the use of restraint or force;
- it is not clear whether the people with parental responsibility are acting in the best interests of the child;
- the proposed care is beyond the scope of parental consent because it is controversial or non-therapeutic (for example sterilisation, organ donation and non-therapeutic male circumcision - see key resources - if parents disagree);
- the courts have stated that they need to review a particular decision;
- the treatment requires detention outside the provisions of mental
- health legislation;
- the people with parental responsibility lack the competence to make the decision;
- the child is a ward of Court, and the proposed step is important; or
- the proposed course of action might breach a person's human rights under the Human Rights Act 1998.

If agreement cannot be reached in a reasonable period, which will depend on the nature and likely course of the patient's condition, lawyers may advise that it is necessary to seek a court order. Parents, and where appropriate, the patient, should be informed and told how to seek legal representation.

How can involving the courts help?

Going to court can be distressing for those concerned and it is essential that ongoing support is provided for the child, the parents, other relatives and carers, and the healthcare team. There are great benefits, however, of a legal system that can give rulings very quickly when necessary. The law can provide a protective role for both patients and the healthcare team who treats them and where there is a disagreement that cannot be resolved.



Can the courts insist on treatment?

In England, Wales, and Northern Ireland the courts have the power to give consent to treatment on behalf of competent and incompetent patients aged under 18. A court can override a child's refusal or parents' refusal of a particular treatment if there is evidence that it would be in the child's or young person's best interests. See, for example, a summary of the case of A NHS Trust v X (In the Matter of X (A Child) (No 2) (2021).

In Scotland, the courts have the same powers to give consent to treatment on behalf of people aged under 16 when they are not competent to give valid consent for themselves. It is unclear whether a Scottish court may override the decision of a child if the medical practitioner believes the child is competent, although it is thought that this is unlikely. Legal advice should therefore be sought.

The courts cannot, however, require doctors to treat contrary to their professional judgement.



Key resources

GMC – <u>0-18 years: guidance for all doctors</u>
BMA – <u>Non-therapeutic male circumcision (NTMC) of children</u> – practical guidance for doctors



Use of restraint when providing treatment

Can doctors restrain children or young people to provide treatment against their wishes?

Once a decision has been made that it is lawful and ethically acceptable to override a refusal of treatment (see section 7.4 on consent and refusal) in principle there cannot be an absolute prohibition on the use of force to carry it out. However, doctors must look at the patient's overall interests, and whether imposing treatment is a proportionate interference given the expected benefits.

What factors should be taken into account when considering the use of restraint?

Doctors should consider if imposing treatment could damage the young person's current and future relationships with healthcare providers and undermine trust in the medical profession. It is important for young people to understand that restraint of any form to provide treatment is used only as a last resort and not until other options for treatment have been explored. The child and the family must be offered continual support and information throughout the treatment period.

If, after spending as much time as is practicable, it is impossible to persuade a child to cooperate with essential treatment, the clinician in charge of the patient's care may decide that restraint is appropriate.

The following points are relevant to any action taken:

- restraint should be used only when it is necessary to give essential treatment or to prevent a child from significantly injuring themselves or others;
- the effect should be to provide an overall benefit to the child, and in some cases, the harms associated with the use of restraint may outweigh the benefits expected from treatment;
- restraint is an act of care and control, not punishment, and should be administered with due respect;
- unless life-prolonging or other crucial treatment is immediately necessary, legal advice should be sought when treatment involves restraint or detention to override the views of a competent young person, even if the law allows doctors to proceed with parental consent;
- all steps should be taken to anticipate the need for restraint and to prepare the child, their family, and staff;
- wherever possible, the members of the healthcare team involved should have an established relationship with the child and should explain what is being done and why;
- treatment plans should include safeguards to ensure that restraint is
 the minimum necessary, that it is for the minimum period necessary to
 achieve the clinical aim, and that both the child and the parents have been
 informed of what will happen and why restraint is necessary;
- restraint should usually be used only in the presence of other staff, who can act as assistants and witnesses; and
- any use of restraint should be recorded in the medical records.



Who is responsible for the decision to use restraint?

Members of the healthcare team should be allowed to express their views and to participate in decision making, although ultimate responsibility rests with the clinician in charge of care. All staff require support and must not be asked to be involved in restraining a child without proper training.

Can children and young people be detained to provide medical treatment?

Detaining children to provide medical treatment raises serious legal issues. Legal advice is essential before children are detained outside the provisions of mental health legislation, and court approval will be necessary. A court asked to rule on such an issue is required to have regard for the young person's rights under the Human Rights Act 1998 and whether, in the circumstances, detention is compatible with these. For example, the right not to be subjected to inhuman or degrading treatment (Article 3), the right to liberty and security (Article 5), and the right to a fair hearing (Article 6).



Confidentiality

When is a duty of confidentiality owed to a child or young person?

A duty of confidentiality is owed to all children and young people. The duty owed is the same as that owed to an adult. As with adults, the duty of confidentiality is not absolute and confidential information can be disclosed when one of the following circumstances applies:

- consent (see section 7.4 on consent and refusal);
- a legal requirement to disclose or the disclosure has statutory authorisation which has set aside the common law duty of confidentiality;
- where there is an overriding public interest.

In addition to the specific circumstances outlined in this guidance that relate only to children and young people, the BMA's confidentiality toolkit provides more detail on the latter two points (see key resources).

When disclosing confidential information healthcare professionals must:

- disclose only the minimum relevant information necessary;
- ensure the disclosure is to the appropriate authority;
- document the disclosure in the medical record;
- be prepared to justify their decisions to disclose (or not to disclose); and
- seek advice from the Caldicott Guardian, Data Protection Officer, or other appropriate senior person if there is uncertainty.

When is a young person competent to consent to the disclosure of their personal information?

In Scotland, anyone aged 12 or over is legally presumed to have such competence. In England, Wales, and Northern Ireland it is also reasonable to presume that children who are aged 12 or over have the competence to give or withhold their consent to the release of information.

Younger children may also be competent to make decisions regarding the control of their health information (see section 7.2 on assessing competence). Healthcare professionals should, unless there are convincing reasons to the contrary, for example, abuse is suspected, respect the child's wishes if they do not want parents or guardians to know about all or some aspects of their healthcare (see section 7.14 on child protection). However, every reasonable effort must be made to persuade the child to involve parents or guardians particularly for important or life-changing decisions.

Are there limits to confidentiality if a child lacks competence?

Occasionally, children who lack competence seek or receive healthcare without their parents or guardians being present. They may lack the competence to give consent to treatment, and the disclosure of information (see sections 7.12 and 7.13, for example, on sexual activity). In these circumstances, confidentiality should usually be respected if they share information on the understanding that the information will not be disclosed to parents or guardians, or indeed to any third party. Parental involvement, however, should be encouraged, unless there are very convincing reasons to the contrary.



There are, however, exceptions to this. For example, when not sharing the information puts the child, or others, at risk of significant harm (see, for example, section 7.14 on child protection). GMC guidance on 0-18s also states: 'You should usually try to persuade the child to involve a parent in such circumstances. If they refuse and you consider it is necessary in the child's best interests for the information to be shared (for example, to enable a parent to make an important decision, or to provide proper care for the child), you can disclose information to parents or appropriate authorities' (paragraph 51).

Where a healthcare professional decides to disclose information to a third party against a child's wishes, the child should generally be told before the information is disclosed. The discussion with the child and the reasons for disclosure should be documented in the child's record.

Can someone with parental responsibility refuse disclosure of a child or young person's personal information?

Anyone with parental responsibility can give or withhold consent to the release of information where the child lacks competence. Where an individual who has parental responsibility refuses to share relevant information with other healthcare professionals or agencies, and the healthcare professional considers that it is not in the best interests of the child, for example if it puts the child at risk of significant harm, disclosure may take place in the public interest without consent (see sections 7.5 and 7.14 on best interests and child protection). Parents should usually be informed of the disclosure, the reasons for it, and the information that will be provided in advance of disclosure.

What if there are concerns a child or young person is at risk of abuse or neglect?

Where healthcare professionals have concerns about a child or young person who may be at risk of abuse or neglect, these concerns must be acted upon, and information given promptly to an appropriate person or statutory body to prevent further harm (see section 7.14 on child protection).

Children and young people may try to elicit a promise of confidentiality from adults to whom they disclose abuse. Doctors must avoid making promises of confidentiality that they cannot keep. Where doctors believe it is important that action is taken, they need to discuss disclosure with the child, and if possible, the child should be given sufficient time to come to a considered decision. If the child cannot be persuaded to agree to voluntary disclosure, and there is an immediate need to disclose information to an outside agency, they should be told what action is to be taken unless doing so would expose the child or others to increased risk of serious harm.

Who can access a child or young person's health record?

Competent children and young people may apply for access to their records or may authorise others to do so on their behalf. Competent patients do not need to give reasons as to why they wish to access their records. If a child lacks competence the GMC, in paragraph 53 of its guidance on 0-18s, advises that: 'In any event you should usually let children access their own health records. But they should not be given access to information that would cause them serious harm or any information about another person without the other person's consent.'



Anyone with parental responsibility may usually exercise their statutory right to apply for access to the child's health records. If the child is capable of giving consent, access may only be given with their consent. It may be necessary to discuss parental access alone with children if there is a suspicion that they are under pressure to agree. For example, the young person may not wish a parent to know about a request for contraceptive advice. If a child lacks the competence to understand the nature of an application but access would be in their best interests, it should be granted. Parental access must not be given where it conflicts with the child's best interests.

Where parents are separated, and both have parental responsibility, and one of them exercises their child's right to access the medical record, doctors are under no obligation to inform the other parent, although they may consider doing so if they believe it to be in the child's best interests. It is advisable to make a note of when, and by whom the record is accessed.



Key resources

BMA – Access to health records

BMA – Confidentiality toolkit

GMC – 0-18 years: guidance for all doctors

GMC – Protecting children and young people: The responsibilities of all doctors



Vaccination

Who can consent to vaccination?

A person aged 16 or 17, or a Gillick competent child, can consent to vaccination. Where someone aged 16 or 17, or who is Gillick competent, consents to vaccination, a person with parental responsibility cannot override that consent. If a person aged 16 or 17 or a Gillick competent child refuses vaccination, that refusal should be accepted. For infants and young children not competent to give or withhold consent, consent can be given by a person with parental responsibility (see section 7.3 on parental responsibility).

What if parents with parental responsibility disagree?

In England and Wales, the UK Health Security Agency *Immunisation against Infectious Disease* (known as the <u>Green Book</u>), advises that vaccination should not be carried out unless both people with parental responsibility can agree to vaccination, or there is a specific court approval that the vaccination is in the best interests of the child (see sections 7.5 and 7.8 on best interests and disputes). This is likely to be the same in Scotland and Northern Ireland.

Who should be present at the vaccination?

A person aged 16 or 17, or a Gillick competent child, can attend vaccination on their own. For infants or children who are not competent, the person with parental responsibility does not need to be present at the time of the vaccination; they may be brought for vaccination by a person without parental responsibility, for example, a grandparent or childminder. There is no requirement for such arrangements to be made in writing. However, the healthcare professional needs to be satisfied that the person with parental responsibility has consented in advance to the vaccination and that they have asked the other person to take the child to the appointment, to consider any further information given by the healthcare professional, and to confirm agreement to vaccination.



Key resources

Department of Health – <u>Immunisation against infectious diseases</u>



Sexual activity

Can a young person consent to treatment associated with sexual activity?

As with other medical interventions, a competent young person may give valid consent to abortion, contraception, and treatment for a sexually transmitted infection, regardless of age or parental involvement, although every reasonable effort must be made to persuade the child to involve their parents or guardians. The courts have also confirmed that a parent's refusal to give consent for an abortion cannot override the consent of a competent young person. With respect to providing contraceptives, doctors should take into account:

- whether the patient is likely to have sexual intercourse without contraception;
- whether the patient's physical and/or mental health is likely to suffer if the patient does not receive contraceptive advice or supplies; and
- whether the patient's best interests would require the provision of contraceptive advice or methods or both without parental consent.

Sexual activity in someone under the age of 13 will always be a cause for concern (see later question). The need to share information without consent to protect the young person must be balanced against the need to provide a service that encourages young people to seek help when they need it.

Where healthcare professionals believe that children may be subject to coercion or exploitation, existing child protection guidelines must be followed. Healthcare professionals with concerns should seek advice and help, anonymously if necessary, from colleagues with expertise in child protection, such as named and designated professionals (see section 7.14 on child protection).

What if the young person lacks competence?

If a young person lacks competence, and it is in their best interests, a person with parental responsibility can legally give consent for the provision of contraception and abortion (provided the legal requirements of abortion legislation are met). If a young person lacks competence to consent to the provision of contraceptives for contraception and the termination of pregnancy, this raises a question about the ability of the young person to consent to sexual intercourse. In cases of doubt, or where the provision of contraception will involve restraint or an invasive procedure, for example, insertion of an IUD, doctors should seek legal advice. If there are concerns that a child is being sexually abused, doctors should follow child protection guidelines.

Does a doctor need to inform the police or social services of all underage sexual activity?

No, only when there are concerns that the young person is being abused (see section 7.13 on some exceptions in Northern Ireland). The GMC states, in its guidance on 0-18s, 'You should usually share information about sexual activity involving children under 13, who are considered in law to be unable to consent. You should discuss a decision not to disclose with a named or designated doctor for child protection and record your decision and the reasons for it' (paragraph 60). While reporting to social services or the police should always be considered when the individual is very young, healthcare professionals are obliged to act in the best interests of the patient, and this requires flexibility. Where a healthcare professional decides to disclose information to a third party against a child's wishes, the child should generally be told before disclosing the information. The discussion with the patient and the reasons for disclosure should also be documented in the patient's record.



Does a doctor need to inform the parents of a young person?

In most cases, no. All children are entitled to have their confidentiality respected, unless there are very convincing reasons to the contrary, for example, if abuse is suspected. However, every reasonable effort must be made to persuade the child to involve their parents or guardians and explore the reasons if the patient is unwilling to do so, particularly for important or life-changing decisions.

Is it legal to provide contraception, sexual and reproductive healthcare without parental involvement?

Many of the principles set out above are supported by statute. For example, the Sexual Offences Act 2003 provides a legal framework aimed at protecting children from sexual abuse. Under the Act, young people under the age of 16 still have the right to confidential advice on contraception, sexual and reproductive health. Most of the Act applies to England and Wales, with a small number of provisions applicable in Scotland and Northern Ireland. Furthermore, the Sexual Offences (Northern Ireland) Order 2008 lowered the age of consent to sexual activity in Northern Ireland from 17 to 16. In addition, it established that the provision of sexual health services to individuals under the age of 16 will not constitute an offence.

What if a doctor disapproves of young people being sexually active?

Doctors must not allow any personal views held about a patient to prejudice their assessment of the patient's clinical needs or delay or restrict the patient's access to care. Doctors should not impose their beliefs on patients. The GMC states in its guidance on 0-18s: 'If carrying out a particular procedure or giving advice about it conflicts with your religious or moral beliefs, and this conflict might affect the treatment or advice you provide, you must explain this to the patient and tell them they have the right to see another doctor. You should make sure that information about alternative services is readily available to all patients. Children and young people, in particular, may have difficulty in making alternative arrangements themselves, so you must make sure that arrangements are made for another suitably qualified colleague to take over your role as quickly as possible' (paragraph 65).

Can sterilisation be performed on children and young people?

Sterilisation is occasionally requested for young women with serious learning difficulties. Although rarer, it may also be suggested as an option for a young man with learning difficulties. Sterilisation for contraceptive purposes should not normally be proposed for young people under 18, given that there are other options available. In the exceptional circumstances in which there is agreement that sterilisation is the best option for a young person, doctors should seek legal advice to obtain a court declaration.



Key resources

GMC – 0-18 years: guidance for all doctors



Sexual activity – additional obligations in Northern Ireland

What is different about the law in Northern Ireland?

Section 5 of the Criminal Law (Northern Ireland) Act 1967 places a duty, unique to Northern Ireland, on everyone to report to the police information they may have about the commission of a relevant offence (one with a maximum sentence of five years or more). There are few exceptions to the law, for example, 'medical confidentiality' is not, in and of itself, understood to be an exception.

If the legal age of consent is 16, does this mean I have to report all underage sexual activity even where the activity is entirely mutually agreed and non-exploitative?

No, you do not have to automatically report all underage sexual activity. The Sexual Offences (Northern Ireland) Order 2008 makes some exceptions to the duty to report. Doctors are not under a duty to report sexual activity involving a child aged 13 to 15 where the other party is under 18.

Where doctors are unsure of their duties and obligations, they should seek advice.

Does it affect my ability to provide contraceptive or sexual health advice to under 16-year-olds?

No, doctors can provide treatment to an under-16-year-old, without automatically having to report the child's sexual activity to the police, where it is to:

- protect a child from sexually transmitted infection;
- protect the physical safety of a child;
- prevent a child from becoming pregnant; or
- promote the child's emotional wellbeing by giving advice.



Child protection

Where doctors have concerns about a child or young person who may be at risk of abuse or neglect, these concerns must be acted upon following local and national guidelines (see key resources box at the end of this section). The best interests of the child or children involved must always guide decision making.

Paragraph 1 of the GMC's guidance on protecting children and young people outlines the following key principles for protecting children and young people:

- a. 'All children and young people have a right to be protected from abuse and neglect all doctors have a duty to act on any concerns they have about the safety or welfare of a child or young person.
- b. All doctors must consider the needs and wellbeing of children and young people this includes doctors who treat adult patients.
- c. Children and young people are individuals with rights doctors must not unfairly discriminate against a child or young person for any reason.
- d. Children and young people have a right to be involved in their own care this includes the right to receive information that is appropriate to their maturity and understanding, the right to be heard and the right to be involved in major decisions about them in line with their developing capacity.
- e. Decisions made about children and young people must be made in their best interests.
- f. Children, young people and their families have a right to receive confidential medical care and advice – but this must not prevent doctors from sharing information if this is necessary to protect children and young people from abuse or neglect.
- g. Decisions about child protection are best made with others consulting with colleagues and other agencies that have appropriate expertise will protect and promote the best interests of children and young people.
- h. Doctors must be competent and work within their competence to deal with child protection issues – doctors must keep up to date with best practice through training that is appropriate to their role. Doctors must get advice from a named or designated professional or a lead clinician or, if they are not available, an experienced colleague if they are not sure how to meet their responsibilities to children and young people'.



Key resources

GMC – <u>Protecting children and young people: The responsibilities of all doctors</u>

GMC – 0-18 years: guidance for all doctors

DFE – Working together to safeguard children Statutory guidance on inter-agency working to safeguard and promote the welfare of children

DFE – Child sexual exploitation Definition and a guide for practitioners

DFE – What to do if you're worried a child is being abused: advice for practitioners

DHNI – <u>Co-operating to Safeguard Children and Young People in Northern Ireland</u>

NICE – Child maltreatment: when to suspect maltreatment in under 18s. NICE clinical guideline 89

RCPCH – Child protection and safeguarding toolkit

RCPCH intercollegiate document – Safeguarding Children and Young

People: Roles and Competences for Health Care Staff

Scottish Government – <u>National Guidance for Child Protection in</u> Scotland



Female genital mutilation

What is female genital mutilation (FGM)?

FGM is a collective term used for a range of practices involving the removal or alteration of parts of healthy female genitalia for non-therapeutic reasons. Different degrees of mutilation are practised by a variety of cultural groups in the UK. FGM has immediate risks, including severe pain, haemorrhage, tetanus and other infections, septicaemia, or even death. In the longer term, girls and women may experience problems with their sexual, reproductive, and general physical and psychological health. The risk of FGM may also give rise to legitimate grounds for an application for refugee or asylum status.

Are there any considerations additional to the usual child protection measures?

FGM is illegal in England, Wales, and Northern Ireland under the Female Genital Mutilation Act 2003 (as amended by the Serious Crime Act 2015) and in Scotland under the Prohibition of Female Genital Mutilation Act 2005 (as amended by the Serious Crime Act 2015). If a child, or young person is identified as being at risk of FGM, urgent safeguarding action must be taken. There is additional legislation and guidance specifically relating to FGM that doctors should be aware of — see key resources below. For example, there is a statutory duty to notify the police of FGM in England and Wales, if a young woman or girl aged under 18:

- informs a healthcare professional that FGM has been carried out on her; or
- a healthcare professional observes physical signs appearing to show FGM.



Key resources

UK-wide:

GMC – <u>Protecting children and young people: The responsibilities of all</u> doctors

Health Education England – <u>FGM e-learning programme (available in all four nations, including for medical students)</u>

RCGP – Female Genital Mutilation

RCOG – <u>Female Genital Mutilation and its Management (Green-top Guideline No. 53)</u>

RCPCH – Female Genital Mutilation Resources

England and Wales:

HM Government – <u>Multi-agency statutory guidance on female genital</u> <u>mutilation</u>

Northern Ireland:

Department of Health – <u>Multi-agency practice guidelines: female</u> genital mutilation

Scotland:

Scottish Government – Violence against women and girls



Compulsory treatment for a mental health condition

When should mental health legislation be used?

In most cases, treatment and support for a young person's mental health condition is provided with consent. In some circumstances, however, mental health legislation can provide a legal structure for compulsory psychiatric care and treatment for a young person's mental health condition, irrespective of whether or not they retain formal decision-making capacity. Compulsory treatment cannot be used to provide treatment for a physical illness unrelated to the mental health condition. Although for some patients a severe mental illness is associated with a corollary lack of capacity, a mental health condition does not automatically diminish a patient's legal capacity.

Doctors who believe that the legislation may apply to one of their young patients but who are unfamiliar with the legislation should seek expert advice.

What legislation is applicable in England and Wales?

The Mental Health Act 1983 (as amended most recently by the Mental Health Act 2007) applies to all children and young people under 18. The Act contains some provisions and specific safeguards for under-18s. Amongst other things:

- 16 and 17-year-olds with capacity cannot have their consent or refusal
 to informal admission to hospital or registered establishment for
 treatment of a mental health condition overridden by those with parental
 responsibility;
- at least one of the people involved in the assessment on admission and treatment under the Act should be a clinician specialising in Child and Adolescent Mental Health Services (CAMHS). Where this is not possible, a CAMHS clinician should be consulted;
- electro-convulsive therapy (ECT) cannot be given without approval of a second opinion appointed doctor even if the child/young person consents to it unless it is an emergency; and
- children and young people detained under the Act must be referred after one year (as opposed to three for adults) for a tribunal hearing.

New legislation is anticipated following the recent independent review of the Mental Health Act. Details of any changes will be posted on the BMA website.

What legislation is applicable in Scotland?

Where a patient is detained, the Mental Health (Care and Treatment) (Scotland) Act 2003 procedures must be followed. The Act contains some provisions and specific safeguards for under-18s. Namely, none of the regulated treatments for a mental health condition may be provided to an incapacitated patient who is 16 or 17 unless either the doctor in charge of care has a qualification, or special experience, in child and adolescent psychiatry or that doctor has sought and obtained an opinion in writing from a doctor who does. In addition, the practitioner appointed by the Mental Welfare Commission must have a qualification, or special experience, in child and adolescent psychiatry or another specialism appropriate for the treatment of the patient.



What legislation is applicable in Northern Ireland?

The Mental Health (Northern Ireland) Order 1986 applies to all children and young people under 18. There are no specific safeguards for under-18s. New legislation combining both mental health and mental capacity law in Northern Ireland has been passed, but the provisions related to mental healthcare have not yet been implemented.



Key resources

England and Wales:

Department of Health – <u>Code of Practice Mental Health Act 1983 (2015)</u> – <u>primarily chapter 19</u>

Scotland:

Department of Health – <u>Mental Health (care and treatment) (Scotland)</u> <u>Act 2003: Code of Practice Volume 1 (2005)</u>



Research and innovative treatment

Can children and young people be involved in research and innovative treatment?

Children and babies should be eligible for inclusion in research and innovative therapy, with appropriate safeguards. To fail to do research would lead to stagnation of current practice and the continuation of medical management by using untried or unproven remedies, based on belief, rather than best evidence. The need for pharmaceutical products specifically designed for use by children has long been recognised. These need to be developed with the involvement of children and young people, once initial studies involving adults have proved the safety and efficacy of the product. There must be no financial reward to the child or parent (expenses are permitted) and all projects must be carefully scrutinised by a Research Ethics Committee (REC).

Who can consent to their involvement in research and innovative treatment?

Families need support and independent advice about their options. The final decision about participation rests with patients (when competent) and with parents. Children and their parents must be given clear and appropriate information, with candid explanations of the purposes, risks and expected benefits of the research. If competent, the child must give unpressured and informed consent. Depending on the nature of the research, and the REC's view, parental consent may also be required, even if the child is competent.

What if the parents consent but the child refuses?

When the procedures are more intrusive than those required for ordinary clinical care, a child's (verbal or non-verbal) refusal is a good reason not to proceed, even if parental consent has been obtained, unless it is in a child's best interests.

What if one parent consents but another refuses?

Legally, the consent of one person with parental responsibility should suffice if the intervention is not contrary to the child's interests, and there are obvious circumstances when the consent of one parent has to be sufficient, for example, because the child is in contact with only one parent. Nevertheless, the reasons for one parent refusing needs to be taken very seriously.

Can children and young people be involved in emergency care trials?

Yes. Children can take part in emergency care trials when there would be no time to seek initial consent before administering the medicine, if certain criteria are met. In 2008, the Medicines for Human Use (Clinical Trials) and Blood Safety and Quality Amendment was passed. As well as amending the Blood Safety and Quality Regulations 2005, this amended the regulations to enable children to be involved in emergency trials in certain circumstances.



Key resources

HRA – Research involving children
MRC and ESRC – Involving children in medical research





8

Confidentiality



Contents

<u>8.1 Introduction to the main principles of confidentiality</u>	207
8.2 Confidentiality: a legal and ethical overview	209
8.3 Disclosing information with consent	211
8.4 Adults lacking capacity	214
8.5 Deceased patients	216
8.6 Disclosures required by law	218
8.7 Public interest disclosures	221
8.8 Exceptional cases where disclosure without consent	
is appropriate to protect adults with capacity who are	
at risk of serious harm	225
8.9 Requests from third parties	226
8.10 Secondary uses of information	228
8.11 Anonymised and pseudonymised information	230
8.12 Security and avoiding inadvertent breaches	232
8.13 Visual and audio images/recordings	235
8.14 Online complaints and the media	237
8.15 Statutory restrictions on disclosure	



8.1

Introduction to the main principles of confidentiality

The duty of confidence

Confidentiality is essential to the relationship of trust between doctors and patients. The principles of confidentiality apply to all doctors irrespective of their speciality. Patients must be able to expect that information about their health which they give in confidence will be kept confidential unless there is a compelling reason that it should not be.

There is a strong public interest in confidentiality as it encourages individuals to seek medical treatment when they need it and freely share information with the healthcare professionals who are providing that treatment. If patients feel they can share information securely for their own care this also ensures there is reliable health information available for approved medical research and health service planning that advances medical knowledge and improves care for patients. The duty of confidentiality extends beyond a patient's death.

Patients also expect that confidential information will be shared with others involved in delivering their care. See 3 on disclosing information with consent.

When does a duty of confidence arise?

'A duty of confidence arises when confidential information comes to the knowledge of a person...in circumstances where he has notice, or is held to have agreed, that the information is confidential...'

Lord Goff. Campbell v MGN Limited (2004)

What information is confidential?

There are various legal definitions relating to 'confidential information' or 'confidential patient information'. The term 'confidential information' is used throughout this guidance to mean information from which patients can be identified and in respect of which a duty of confidence is owed, including information about deceased patients.

'All identifiable patient data held by a doctor or a hospital must be treated as confidential.'

W,X,Y,Z v. Secretary of State for Health (2015)

Demographic information provided by patients for the purpose of registering for, or receiving, healthcare as well as clinical information, is confidential. Even where demographic information is held separately from clinical information, such as a list of patients' names and addresses, it is equally subject to the duty of confidence.



8.1

Confidential information can be held in written, digital, visual, or audio form or simply information held in the memory of healthcare professionals. It covers (non-exhaustively):

- NHS Number, or Community Health Index (CHI) number, and names and addresses or other demographic information used to identify patients;
- any clinical information about an individual's diagnosis or treatment;
- a picture, photograph, video, audiotape, scans, ECHGs or other images of the patient or their tests;
- who the patient's doctor is and what clinics the patient attends and when;
 and
- anything else that may be used to identify a patient directly or indirectly.

When can confidential information be disclosed?

The duty to maintain confidentiality can present healthcare professionals with an ethical or legal dilemma, commonly when a third party requests information about the patient or their treatment. The duty of confidentiality is not absolute and confidential information can be disclosed when one of the following circumstances applies:

- the patient has capacity to consent and consents to the disclosure. This can be either:
 - implied consent for an individual's direct care; or
 - explicit consent (see section 8.3);
- the law requires disclosure (see section 8.6);
- the duty of confidentiality has been set aside under section 251 of the NHS Act 2006 (see section 8.10); or
- where there is an overriding public interest, that is, where disclosure is
 essential to prevent serious harm to the individual or a third party or to
 prevent or detect a serious crime in accordance with GMC guidance
 (see section 8.7).

Making a disclosure

When making a disclosure of confidential information for purposes other than a patient's direct care, healthcare professionals must:

- ensure that one of the above circumstances applies;
- disclose only the minimum relevant information necessary;
- ensure the disclosure is to the appropriate authority;
- document the disclosure and the reason for it in the medical record;
- be prepared to justify their decisions to disclose (or not to disclose);
- consider and satisfy the Caldicott Principles; and
- seek advice from the Caldicott Guardian if there is uncertainty (trainees should refer to a senior consultant or GP partner).



8.2

Confidentiality: a legal and ethical overview

The legal framework which applies to confidential information combines common law and statutes, for example the General Data Protection Regulation (GDPR) and the Human Rights Act (HRA) 1998. The legal framework is supplemented by ethical and professional guidance from regulatory bodies and obligations under contracts of employment. When considering questions about confidentiality, healthcare professionals must look at the overall effect of the law, ethical guidance and their contractual obligations, not just each aspect in isolation.

Disclosure of, and access to, confidential information is governed by the below, all of which are reflected throughout this guidance.

The Common Law

The common law is based on previous decisions about the law made in court by judges — sometimes referred to as 'judge-made law'. Under the common law duty of confidentiality, if information is received in confidence, including where it is reasonably expected that a duty of confidence applies, that information cannot normally be disclosed without patient consent unless it is required by law (section 8.6), when the duty of confidentiality is set aside via section 251 of the NHS Act 2006 (section 8.10), or where there is an overriding public interest (section 8.7).

Human Rights Act 1998

A right to 'respect for private and family life' is guaranteed in article 8 of the HRA. This right is not absolute, and may be set aside by the state where the law permits and 'where necessary in a democratic society in the interests of national security, public safety or the economic well being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others'. The effect is similar to that of the common law: privacy is an important right which must be respected, but interference with it can be justified in certain circumstances.

Data Protection Act 2018 and the UK General Data Protection Regulation

The Data Protection Act 2018 (DPA) is the primary piece of data protection legislation in the UK and incorporates the GDPR into UK law. The DPA sits alongside, and supplements, the UK GDPR. It applies to all personal data relating to living individuals, including confidential information.

The DPA regulates the processing of personal data about living individuals including disclosing, holding, or using information. It applies to paper records, digital information, and images of individuals. A fundamental requirement of UK GDPR is transparency. As part of satisfying transparency requirements, healthcare organisations must use privacy notices which are easy for patients to find and which explain how confidential information is used and shared.

The BMA has separate guidance on UK GDPR which outlines how to handle special category health data (see key resources). If you are a GP data controller under UK GDPR it is particularly important that you familiarise yourself with this guidance.



Access to Health Records Act 1990

The UK GDPR and DPA do not cover the records of deceased patients. Rights of access to deceased patients' health records are contained within the Access to Health Records Act 1990 and Access to Health Records (Northern Ireland) Order 1993. Personal representatives (executors or administrators of the estate of a deceased person) have the right to access the deceased's health records. A person who may have a claim arising from the death of the deceased may also access the deceased's health records, but their access is limited to information which is directly relevant to the claim.

National Health Service Act 2006

In England and Wales, regulations under section 251 of the NHS Act 2006 permit certain disclosures to occur without a breach of the common law duty of confidentiality.

The Health Service (Control of Patient Information) Regulations 2002 can provide statutory support to enable health service management and medical research when it is not practical to obtain consent and anonymised information cannot be used. Disclosures under these regulations are commonly referred to as having 'section 251 support' (see section 8.10).

Computer Misuse Act 1990

It is an offence under the Computer Misuse Act to gain unauthorised access to computer material. This includes using another person's ID or login details and password without authority in order to do so, or to alter or delete data.

Caldicott Principles

There are eight good practice <u>Caldicott Principles</u> which apply to all confidential data collected for the provision of health and social care services. Organisations providing publicly funded health or care services should appoint a Caldicott Guardian whose role is to help their organisation to uphold the Caldicott Principles.

Contract of employment

Confidentiality of patient information is a requirement of NHS employment contracts and the employment contracts of independent providers of NHS services. Staff employed by the NHS may face disciplinary action by their employer if they breach confidentiality.

Professional and ethical standards

All healthcare professionals must maintain the standards of confidentiality laid down by their professional body, such as the General Medical Council (GMC) and Nursing and Midwifery Council (NMC), or risk complaint for professional misconduct which may result in a reprimand or removal from the register.



Key resources

BMA – GPs as data controllers under GDPR

BMA – Access to health records

UK Caldicott Guardian Council – A manual for Caldicott Guardians



8.3

Disclosing information with consent

Consent to disclosure may be implied or explicit. In either case, consent should be informed and freely given.

When can consent be implied?

Healthcare professionals rely on implied consent when sharing information for the direct care of an individual patient (unless the patient has indicated an objection). This well-established practice is based on the understanding that patients will expect that those providing them with direct care will have access to information needed to support the safe and effective provision of their care.

What is direct care?

Direct care activities are those that directly contribute to the diagnosis, care (including preventative care), and treatment of an individual patient.

Those providing direct care are considered to have a 'legitimate relationship' with the individual patient. This includes non-healthcare professionals, such as social workers, and clerical staff, when they are involved with the provision of direct care to the patient. Information sharing amongst those with a legitimate relationship is acceptable to the extent that health and care professionals only share relevant information on a 'need to know' basis.

Local clinical audits are an integral part of direct care. They can therefore be conducted with implied consent provided the audit is carried out by a clinician with a legitimate relationship with the patient (and where it is not possible to use anonymised information).

When is a legitimate relationship created?

A legitimate relationship is created with a registered and regulated health or social care professional when any or all of the following criteria are met:

- the individual presents themselves to the professional to receive care;
- the individual agrees to a referral from one care professional to another;
- the individual is invited by a professional to take part in a screening or immunisation programme for which they are eligible and they accept;
- the individual presents to a health or social care professional in an emergency situation where consent is not possible;
- the relationship is part of a legal duty, for example, contact tracing in public health; and/or
- $\;$ the individual is told of a proposed communication and does not object.

Read more in the Caldicott Review (see key resources).

The question of when a legitimate relationship is created is particularly important in the context of integrated care models or multi-agency working. The basic rule is that if a legitimate relationship has not been created, consent for records to be accessible across organisational boundaries cannot be implied. There may be some exceptions to this for local out of hours service arrangements, including out of hours pharmacies, when certain information such as current medication, allergies, and key medical history can be shared.



8.3

'No surprises'

When considering sharing information for direct care reasons a useful rule of thumb to apply is that patients should not be surprised to find out who has been given access to their information. To ensure there are 'no surprises', and for implied consent to be valid, it is important that patients are informed about how their information is shared and that they can object. It is important that when sharing information with implied consent healthcare professionals do not go beyond the purposes which a patient has been informed about and might reasonably expect. One way to help ensure 'no surprises' is via the use of privacy notices which explain how information is used and shared and which are an essential requirement of the UK GDPR.

Importance of sharing for direct care

'The duty to share information for individual care is as important as the duty to protect patient confidentiality.' Principle 7, The Caldicott Principles.

It can be frustrating for patients to repeat the same information to multiple healthcare professionals. In England, the Health and Social Care (Safety and Quality) Act 2015 imposes a statutory duty on healthcare providers and commissioners to share information for the provision of health or care to an individual. This duty does not override the obligations of the common law duty of confidentiality. For the provision of direct care this means the patient's implied consent is required as described above.

Can patients object to sharing information for direct care?

Yes. The objection of an adult patient with capacity to information sharing for direct care purposes should be respected (unless, in rare circumstances, there is a public interest justification for the disclosure, see section 8.7). Any refusal of disclosure must be documented in the medical record.

The potential consequences of the patient's refusal to share with others providing their care should be explained to them and options for compromise explored. Ultimately, it may not be possible to refer or treat the patient if it would be unsafe or harmful to do so without disclosing information.

When is explicit consent needed?

If the sharing is not among the health and care team who are providing (or have provided) direct care to the patient, explicit consent is required unless there is another lawful justification in place (see section 8.1). Explicit consent is achieved when a patient actively provides consent, either orally or in writing. A common example of when explicit consent is required is for disclosures to local councils providing housing or benefits services.



8.3

HIV and Sexually Transmitted Infections (STIs)

Information disclosed by a patient to a dedicated sexual health service should not be shared with other healthcare professionals, including the patient's GP, without the patient's explicit consent.

Other health services which provide STI and HIV treatment must inform patients about how their information will be shared, including how information will be accessible within a shared care record. If HIV/STI information is to be shared on the basis of implied consent, healthcare professionals must be confident that the patient has a reasonable expectation that this will happen. A patient's choice not to share information with other health and care professionals involved in their care must be respected, unless the disclosure can be justified in the public interest (see section 8.7).



Key resources

Caldicott F – <u>To share or not to share? The information governance</u> review

GMC – Confidentiality: good practice in handling patient information



8.4

Adults lacking capacity

Healthcare professionals have the same duty of confidentiality to all their patients regardless of age or disability. Patients with mental health problems or learning disabilities must not automatically be regarded as lacking capacity to give or withhold their consent to the disclosure of confidential information.

The BMA has separate guidance on treating adults who lack capacity (see key resources).

In the absence of a health and welfare attorney or other lawful proxy decision maker, healthcare professionals may only disclose information on the basis of the incapacitated patient's best interests or, in Scotland, where it provides a 'benefit' to the patient. Where patients lack mental capacity to consent to disclosure, it is usually reasonable to assume that patients would want people close to them to be given information about their illness, prognosis, and treatment unless there is evidence to the contrary. However, where there is evidence that the patient did not want information shared, this must be respected.

Those close to the patient who lacks capacity have an important role to play in decision making whether they have a formal role as a proxy decision maker, or a more informal role such as helping the healthcare team to assess the patient's best interests. It might, however, be more difficult to carry out these roles without some information being provided about the medical condition of the patient.

Proxy decision makers

Legally-appointed proxy decision makers have the right to give or withhold consent to treatment and so must be involved in treatment decisions, although where emergency treatment is required this may not always be possible or practicable. Legally-appointed proxy decision makers include welfare attorneys and court-appointed deputies whose authority extends to medical decisions and persons authorised under an intervention order or welfare guardians with powers relating to the medical treatment in question. It follows that they have rights of access to sufficient information to enable them properly to make the decisions they are charged with.

Independent mental capacity advocates (IMCAs) – England and Wales

Where a patient in England and Wales lacks capacity and has no relatives or friends who can be consulted - or whom it is appropriate to consult – the MCA requires an IMCA to be appointed and consulted about all decisions about 'serious medical treatment', or place of residence. The healthcare team must provide the IMCA with all the relevant information including the risks, benefits, side effects, likelihood of success and level of anticipated improvement if treatment is to be given, the likely outcome if treatment is withheld, and any alternatives that might be considered.

While it will therefore be necessary for all lawful proxy decision makers to have information that will enable them to act or make decisions on behalf of the patient, it does not mean that they will always need to have access to all the patient's records. Only information relevant to the issue in question should be disclosed.



8.4

Relatives, carers, and friends

If a patient lacks capacity, healthcare professionals may need to share information with relatives, friends, or carers to identify the care or treatment that is in the patient's overall best interests, or that will benefit the patient. 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 they have not given explicit consent. This does not however mean that all information should be routinely shared and, where the information is particularly 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.

Disclosures to protect adults who lack capacity

There are certain legal requirements to disclose information about an adult who may be at risk of harm (see section 8.6).

In the absence of a legal requirement, where adults lack the capacity to make a decision about whether or not to disclose information relating to harm or abuse, decisions need to be made on their behalf. Decisions can be made by a legally appointed proxy or (if one is not available) relevant healthcare professionals can make a decision based upon an assessment of the individual's best interests or of what would be likely to benefit them.

When considering a disclosure of information, any assessment of best interests or benefit will ordinarily involve discussion with those close to the individual. In relation to domestic abuse, however, care has to be taken to ensure that anyone consulted who is close to the individual is in fact acting in the person's interests.

Healthcare professionals must disclose information to the appropriate authority where there is a belief that an adult lacking capacity is at risk of abuse or other serious harm, unless it is not in the overall best interests of the patient to do so.

Where attorneys appear to be making decisions that are clearly not in the best interests of the individual, and the problems cannot be resolved locally, the matter should be referred in England and Wales to the Court of Protection. In Scotland, decisions about medical treatment are open to appeal to the sheriff and then, by leave of the sheriff, to the Court of Session. Further information is available from the Scottish Mental Welfare Commission.

Disclosures to the Office of the Public Guardian (OPG) (England and Wales)

In England and Wales, the Office of the Public Guardian (OPG), or a Court of Protection visitor acting on the instructions of the OPG, may ask a healthcare professional to see a patient's records while it is investigating the actions of a deputy or attorney. For example, the OPG may want to establish the mental capacity of a patient at a particular time. If healthcare professionals can release this information promptly, it can help ensure these investigations are completed as quickly as possible. If the request from the OPG concerns a patient who has capacity however, explicit consent for disclosure from the patient must be sought.



Key resources

BMA – Mental Capacity Act toolkit

 $BMA-\underline{Adults\ with\ incapacity\ Scotland\ toolkit}$

BMA – Mental capacity in Northern Ireland toolkit



8.5

Deceased patients

Are deceased patients owed a duty of confidentiality?

Yes. The obligation to respect a patient's confidentiality extends beyond death. However, this duty needs to be balanced with other considerations, such as the interests of justice and of people close to the deceased person. There may be some circumstances where it is obvious that there may be some sensitivity about information in health records. In these limited circumstances healthcare professionals may wish to consider speaking to their patients about the possibility of disclosure after death with a view to soliciting their views about disclosure.

Are there any rights of access to a deceased patient's records?

Statutory rights of access are contained within the Access to Health Records Act 1990 (AHRA) and the corresponding legislation in Northern Ireland, the Access to Health Records (Northern Ireland) Order 1993.

There are two distinct groups who have rights of access to information within the deceased's record:

- personal representatives; and
- anyone who may have a claim arising out of a patient's death.

It is necessary to consider access requests by these two groups separately. A personal representative (the executor or administrator for the estate of a deceased person) does not need to have a claim arising out of the death to access the deceased's medical record. This right of access extends to all information within the record with limited exceptions (see below). Personal representatives do not need to provide a reason for seeking access to the record, although the record-holder must be able to establish that the requestor is indeed the personal representative.

Those who do not have the status of personal representative but may have a claim arising out of the death of the patient, for example an insurance claim, have a right of access only to information which is directly relevant to the claim.

The BMA encourages doctors to adopt an ethical approach to handling requests from personal representatives so that a balance can be achieved between the duty of confidentiality to the deceased and compliance with the legal duty to provide access. In order to maintain confidentiality as far as possible, the BMA advises that when personal representatives request access, it is appropriate to enquire why access is required and whether the request can be satisfied by providing access only to information which is relevant for the purpose. Ultimately, if the personal representative chooses not to provide a reason for access and insists on access to the full record, doctors must comply with these requests to comply with the law.



When should information not be disclosed?

Information requested by personal representatives and others with a claim arising out of the death should not be disclosed if:

- it identifies a third party without that person's consent unless that person is a healthcare professional who has cared for the patient;
- the patient provided it in the expectation that it would not be disclosed to the particular individual making the application;
- it is the result of a particular examination or investigation which the patient consented to in the expectation that it would not subsequently be disclosed;
- in the opinion of the relevant healthcare professional, it is likely to cause mental or physical harm to an individual; or
- the record includes a note, made at the patient's request, that the patient did not wish access to be given.

Who is responsible for providing access?

Medical records of the deceased might be sent to relevant local archive bodies, however, where a provider, such as a GP practice, still holds the record it is obliged to respond to requests under the AHRA (or corresponding legislation in Northern Ireland). Our guidance on access to health records provides more detail on who must give access under the legislation (see key resources).

Are there any other circumstances when information about a deceased patient must be disclosed?

Yes. Separate to the access to health records legislation, information about a deceased patient must be disclosed:

- to assist a coroner or procurator fiscal investigation;
- for accurate completion of death certificates;
- to meet a statutory duty of candour; or
- when the law requires disclosure.

Are relatives entitled to information about the deceased's last illness?

Whilst there is no legal entitlement other than the limited circumstances covered under access to health records legislation, healthcare professionals have always had discretion to disclose information to a deceased person's relatives or others when there is a clear justification. A common example is when the family requests details of the final illness because of an anxiety that the patient might have been misdiagnosed or there might have been negligence. Disclosure in such cases is likely to be what the deceased person would have wanted and may also be in the interests of justice. Refusal to disclose in the absence of evidence that this was the deceased patient's known wish exacerbates suspicion and can result in unnecessary litigation. In other cases, the balance of benefit to be gained by disclosure to the family, for example, of a hereditary or infectious condition, may outweigh the obligation of confidentiality to the deceased.



Key resources

BMA – Access to health records

GMC – Confidentiality: good practice in handling patient information



8.6

Disclosures required by law

Certain statutes and the courts can require healthcare professionals to disclose confidential information, regardless of patient consent. The statutory requirements which healthcare professionals are most likely to encounter are summarised below.

Healthcare professionals must be aware of their obligations to disclose in these circumstances as well as to ensure that they do not disclose more information than is necessary.

Where healthcare professionals have concerns about a disclosure which is legally required, advice can be sought from the Caldicott Guardian or the National Data Guardian.

What statutory requirements to disclose are healthcare professionals most likely to encounter?

Management of health and care services

Health and Social Care Act 2012 (England only)
 NHS England has powers under the Health and Social Care Act to require confidential information from healthcare providers in certain circumstances. This will usually be in response to directions from the Secretary of State for Health and Social Care or NHS England.

Public health

- Public Health (Control of Disease) Act 1984 / Health Protection (Notifications) Regulations 2010 (England only)
- Public Health (Northern Ireland) Act 1967
- Public Health etc (Scotland) Act 2008
- Health Protection (Notification) (Wales) Regulations 2010

Healthcare professionals have a statutory duty to report certain notifiable diseases, including infectious diseases and food poisoning, to the appropriate body.

Adults at risk of harm

- Care Act 2014 (England only)
- Adult Support and Protection (Scotland) Act 2007
- Social Services and Well-being (Wales) Act 2014

When requested, healthcare professionals are required to disclose relevant information to adult safeguarding boards or local authorities in relation to enquiries about adults considered to be at risk of, or to have suffered from, abuse or neglect. The requirement to disclose under this legislation applies regardless of whether the adult lacks the capacity to make the decision.

Counter-fraud

- National Health Service Act 2006 and the National Health Service (Wales)
 Act 2006
 - The NHS Counter Fraud Authority has powers to require the production of documents to prevent, detect, and prosecute fraud in the NHS.
- Local Audit and Accountability Act 2014 (England only)
 Confidential information can be required by the government for fraud-prevention data-matching exercises.



8.6

Female genital mutilation (FGM)

Female Genital Mutilation Act 2003 (as amended by the Serious Crime Act 2015) (England, Wales, and Northern Ireland)
In addition to general safeguarding obligations and duties to report in the UK, in England and Wales there is a statutory duty to notify the police when it is identified that an under 18-year-old has had FGM. See our guidance on children and young people (see key resources) for more on this issue.

There is no specific statutory duty to report in Northern Ireland, however, the Criminal Law Act would apply – see below.

Regulation of healthcare services

- Health and Social Care Act 2008 (England and Wales)
- Public Services Reform (Scotland) Act 2010
- Health and Personal Social Services (Quality, Improvement and Regulation)
 (Northern Ireland) Order 2003

Regulatory bodies have powers to access confidential information when it is necessary to perform their regulatory functions.

In Northern Ireland, there are some restrictions on the disclosure of confidential information which mean that identifiable information can be disclosed only in cases of serious risk to individuals.

Investigations by regulatory bodies

- Medical Act 1983

The General Medical Council has powers under section 35A of the Medical Act 1983 (as amended) to require disclosure of information relevant to the discharge of fitness to practise functions. The Nursing and Midwifery Council has similar powers.

Northern Ireland: Criminal offences

- Criminal Law Act (Northern Ireland) 1967

There is a duty on all citizens to report to the police information they may have about the commission of a relevant offence (in other words, one with a maximum sentence of 5 years or more). This includes a duty to report sexual activity where an over 18-year-old has sex with a young person under 16.

The duty does not arise where a person has a 'reasonable excuse' not to disclose the information. 'Medical confidentiality' is not, in and of itself, understood to be a 'reasonable excuse'.



8.6

Other legal requirements to disclose

Healthcare professionals may also encounter the below statutory requirements to disclose.

- Abortion Regulations 1991 (England and Wales) (and amendments);
 Abortion (Scotland) Regulations 1991; and Abortion (Northern Ireland)
 (No.2) Regulations 2020;
 - A doctor carrying out a termination of pregnancy must notify the Chief Medical Officer giving a reference number and the date of birth or age and postcode of the person concerned;
- Reporting of Injuries, Diseases and Dangerous Occurrences Regulations 2013 (UK-wide)
 - Employers or those in charge of work premises must report deaths, major injuries, and accidents to the Health and Safety Executive (this duty to report does not extend to doctors who are not employers);
- Road Traffic Act 1988 (UK-wide)
 Healthcare professionals must provide to the police on request information which may identify a driver alleged to have committed a traffic offence; and
- Terrorism Act 2000 (UK-wide)
 All citizens, including healthcare professionals, must inform police as soon as possible, of any information that may help to prevent an act of terrorism, or help in apprehending or prosecuting a terrorist.

Can patients opt-out of disclosures which are required by law?

No. Patients do not have the right to refuse disclosures which are required by law.

Disclosure to the courts

Courts, including coroner's investigations, have legal powers to require disclosure without patient consent.

Once they have received a court order requiring them to disclose information, healthcare professionals have to comply with it if they think if falls within the scope of what the court needs, however, they should not disclose beyond what has been requested. Refusal to disclose the information can be an offence. If healthcare professionals think information should not be disclosed because, for example, it reveals confidential material about a third party unrelated to the case in hand, they should object to the judge or presiding officer.

Patients must also be given the opportunity to object. If the application is served on a healthcare organisation, rather than an individual patient the patient should be informed of the application so they can make their representations to court if they object.



Key resources

BMA – <u>Children and young people toolkit</u>

GMC – Confidentiality: good practice in handling patient information



8.7

Public interest disclosures

When can information be disclosed in the public interest?

Public interest is the general welfare and rights of the public that are to be recognised, protected, and advanced.

According to GMC guidance a disclosure of confidential information because it is in the 'public interest' may be justified if it is essential to:

- prevent, detect, or prosecute serious crime;
- prevent a serious threat to public health or national security; or
- protect individuals or society from serious harm.

In the absence of patient consent, a legal requirement or statutory authorisation, and when the information cannot be anonymised, any decision to disclose confidential information to third parties must be justifiable in the public interest.

Disclosures in the public interest will generally be cases which relate to a single individual's information. Decisions about public interest disclosures must be made on a case-by-case basis. The public interest test cannot be used to justify routine or ongoing disclosures.

Ultimately, the 'public interest' can only be determined by the courts. However, when considering disclosing information in the public interest, healthcare professionals must consider how the benefits of making that disclosure outweighs both the patient's and the public interest in keeping the information confidential. GMC guidance states that when carrying out this balancing exercise doctors must consider (not exhaustive):

- the potential harm or distress to the patient arising from the disclosure;
- the potential harm to trust in doctors generally:
- the potential harm to others if the information is not disclosed; and
- the potential benefits to an individual or society arising from the disclosure of information.

Healthcare professionals must also:

- assess the urgency of the need for disclosure;
- persuade the patient to disclose voluntarily, where appropriate;
- inform the patient before making the disclosure, unless it is unsafe do so or if it would inhibit effective investigation;
- disclose the information promptly to the appropriate body;
- reveal only the minimum information necessary to achieve the objective;
- be assured that the information will be used only for the purpose for which it is disclosed;
- document in the medical record the reasons for disclosing the information without consent (or a decision not to disclose); and
- be able to justify the decision.



8.7

Healthcare professionals should be aware that they risk criticism or sanctions if they fail to take action to avoid serious harm. Advisory bodies, such as the BMA, cannot tell healthcare professionals whether or not to disclose information in a particular case. They can provide general guidance about the categories of cases in which decisions to disclose may be justifiable. Guidance should be sought from the Caldicott Guardian, senior colleagues, and/or medical defence body where there is any doubt as to whether disclosure should take place in the public interest.

Public interest disclosures will invariably engage one or more of the below considerations.

Is the disclosure necessary to prevent, detect, or prosecute serious crime?

A disclosure in the public interest can be made when it is necessary to prevent, detect, or prosecute serious crime. There is no legal definition as to what constitutes a 'serious' crime. In the BMA's view, serious crime includes murder, manslaughter, rape, treason, kidnapping, violent assault, and abuse of children or similar acts which have a high impact on the victim. Serious harm to the security of the state or to public order and serious fraud will also fall into this category.

A disclosure for serious fraud might be justifiable depending on the facts of the case, for example, serious fraud involving significant NHS resources is likely to harm individuals waiting for treatment. Prescription fraud might be serious, for example if prescriptions for controlled drugs are being forged a disclosure may be justified. In contrast, theft, minor fraud, or damage to property where loss or damage is less substantial is highly unlikely to warrant a breach of confidence.

All healthcare professionals should be aware that even where a crime is 'serious', this fact would not in isolation justify a disclosure on public interest grounds. Healthcare professionals must conduct a balancing exercise involving careful consideration of all relevant factors (see above) in reaching a decision whether the public interest test for disclosure in GMC guidance is met.

Is the disclosure necessary to prevent serious harm?

It is important to distinguish between serious harm to the individual to whom the information relates and serious harm to third parties.

Adults with capacity generally have the right to consent or refuse consent to disclosures of information which expose them (but no one else) to risks of serious harm (see section 8.8).

In some situations, it may not be possible to seek consent from an adult with capacity, and a disclosure in the public interest is likely to be justifiable to prevent serious harm. An example is when the police are investigating an unexplained disappearance of an individual and have concerns about their safety.

Confidential information can be disclosed without consent to prevent serious harm or death to third parties. Such situations could arise, for example, in domestic violence situations where a child is at risk (see section 8.8).

Or, if a doctor believes a work place is unsafe and the Health and Safety Executive need identifiable information in order to investigate, a disclosure of confidential information in the public interest may be justifiable.



8.7

When can information be disclosed to the DVLA or DVA?

Disclosures to the Driver and Vehicle Licensing Authority (DVLA) or Driver and Vehicle Agency (DVA) can be made on public safety grounds. Where a patient has an illness or condition which makes them medically unfit to drive, a prompt disclosure of relevant information should be made to the DVLA or DVA if:

- the patient cannot be persuaded to discontinue driving; or
- the healthcare professional is aware that the patient continues to drive.

Disclosure to the DVLA or DVA is not mandatory, but healthcare professionals must consider whether non-disclosure in relation to a foreseeable and serious threat could leave them open to a possible charge of negligence if grave harm results from the non-disclosure.

Before contacting the DVLA or DVA the doctor should try to inform the patient of their intention to disclose.

Can disclosures be made to prevent the spread of serious communicable diseases?

When a patient has a medical condition that puts others at risk, for example, at risk of infection, healthcare professionals must discuss with the patient how to minimise the risk to others. In the case of serious communicable diseases, healthcare professionals should discuss with the patient how to protect others, for example, in the case of sexually transmitted infections the need for them to inform sexual partners, and the options for safe sex.

Exceptionally, if patients refuse to modify their behaviour or inform others, doctors are advised by the GMC that they may breach confidentiality and inform those at risk of infection, for example a close sexual contact of a patient. Wherever possible, patients should always be told before this step is taken.

There are certain legal requirements, with which public health doctors will be familiar, to disclose information about notifiable diseases to the relevant appropriate bodies for disease control and surveillance purposes (see section 8.6).

Injuries to colleagues

The use of universal precautions should be enough to protect healthcare workers from infection, thereby making disclosure unnecessary to prevent serious harm. However, there will be occasions where, for example, despite all reasonable precautions a healthcare professional suffers a needlestick or similar injury and the patient is known by the treating doctor to have a bloodborne virus. If the patient has capacity, consent should be sought to disclose information about their infection status.

If the patient cannot be persuaded to consent to disclose their infection status, or if it is not practicable to ask for their consent, the GMC advises that information can be disclosed if it is justified in the public interest. This could be, for example, if the information is needed for decisions about the continued appropriateness of post-exposure prophylaxis.

The BMA has separate guidance on testing adults who lack capacity in the event of a needlestick injury (see key resources).



8.7

Can patients object to disclosures in the public interest?

No. If the benefits of the disclosure to an individual or to society outweigh both the public and the patient's interest in keeping the information confidential, the disclosure can occur even in the face of a patient's objection.

The national data opt-out (where patients in England can register to optout of their confidential information being used for research and planning purposes) does not apply where there is an overriding public interest in disclosure. (See section 8.10 for more on the national data opt-out.)

Legal duty to consider a disclosure in the public interest

In rare cases, where a doctor is in a relationship of 'close proximity' with an individual who might benefit from the disclosure of patient information (for example, because knowledge of their genetic risk would enable them to take steps to avoid passing on this condition to their offspring), the doctor could be under a legal duty to balance the duty of confidentiality against the benefits of disclosure in a particular case. (The BMA understands that a relationship of 'close proximity' includes the doctor-patient relationship and, also rare circumstances where a doctor might have a duty of care to a third party.)

If a doctor has carried out the balancing exercise properly, in accordance with professional guidance, and has reasonably concluded that a disclosure should not be made, they will have fulfilled their duty of care. This legal duty reinforces GMC guidance, and the guidance in this section, when doctors face difficult situations whereby the disclosure of a patient's confidential information may benefit others who are at risk. The balancing exercise between benefits and harms must be carried out before a decision to disclose or not to disclose is made.



Key resources

BMA – <u>Needlestick injuries and blood-borne viruses: decisions about testing adults who lack the capacity to consent</u>

GMC – Confidentiality: good practice in handling patient information GMC – Confidentiality: disclosing information about serious

communicable diseases

GMC – <u>Confidentiality</u>: <u>patients' fitness to drive and reporting concerns</u> <u>to the DVLA or DVA</u>



8.8

Exceptional cases where disclosure without consent is appropriate to protect adults with capacity who are at risk of serious harm

Healthcare professionals can receive requests for information from the police, social services or partnership organisations, such as multi-agency risk assessment conferences (MARACs) in relation to protecting adults who are at risk, or are a victim, of abuse or domestic violence. These requests can present challenging situations where adults with capacity do not want confidential information disclosed, even where this would be the best way to ensure they are protected from harm.

Is consent needed for disclosures to protect adults with capacity from risk of harm?

Whenever doctors seek to disclose confidential information about adults with capacity who are at risk of harm, they should first consider whether they can obtain consent (unless there is a legal requirement to share).

In the BMA's view, adults with capacity have the right to make decisions about how they manage the risks to which they are exposed. Such decisions should ordinarily be respected even where a decision leaves them (but no one else, such as a child) at risk of serious harm. A refusal of disclosure by a patient should not result in the patient being abandoned by services, and continuing care and support should be offered.

In some situations, healthcare professionals may consider disclosing information without consent in the public interest in order to protect adults who have capacity where they have a reasonable belief that the individual will be the victim of serious crime such as violent assault. In these circumstances, healthcare professionals should keep in mind the difficulty of prosecuting a crime where the victim refuses to participate with the criminal justice system, as well as the impact of disclosure on the patient's trust in the profession.

Given the difficulties associated with preventing crime where the victim refuses to cooperate, disclosure of information without consent in these circumstances is likely to be exceptional. Any healthcare professional considering disclosure in these circumstances should take advice from a Caldicott Guardian or appropriate professional, regulatory, or medical defence body and make contemporaneous notes of the decision they make and the reasons behind it.

The advice above relates to situations where only an adult with capacity is at risk. Where others, such as a child or adult lacking capacity are also at risk, a disclosure in the public interest is likely to be justified even in the face of refusal by an adult patient with capacity (see section 8.7).



Key resources

BMA – <u>Adults at risk and confidentiality</u>

GMC – <u>Confidentiality</u>: good practice in handling patient information



8.9

Requests from third parties

Doctors receive frequent requests for access to confidential information from third parties for purposes which are unrelated to the provision of healthcare. When third parties ask for confidential information, doctors must have written consent from the patient, or a person properly authorised to act on the patient's behalf, unless there is another lawful basis for the disclosure, such as a disclosure made in the public interest (see section 8.7).

For disclosures with consent, evidence of consent should be provided by the third party. An electronic copy of a signed form is sufficient, provided that the third party can satisfy the doctor that the form has not been tampered with in any way.

Solicitors

A patient with capacity can authorise a solicitor to make a subject access request (SAR) under UK GDPR on their behalf. As is the case for all SARs, the identity of the person making the request must be verified. Healthcare professionals should treat a request from a patient's legitimately authorised solicitor in the same way as a request from the patient themselves. Solicitors must provide the patient's written consent. The consent must cover the nature and extent of the information to be disclosed (for example, past medical history), and who might have access to it as part of the legal proceedings. Where there is any doubt, healthcare professionals should confirm with the patient before disclosing the information.

Standard consent forms have been issued by the BMA and the Law Society of England and Wales and the Law Society of Northern Ireland (included in the BMA's access to health records guidance - see key resources).

Employers and insurance companies

Insurance companies and employers should use the provisions of the Access to Medical Reports Act 1988 to seek a GP report. Prior to disclosing information to insurers and employers, healthcare professionals must be provided with evidence of the individual's written consent, or authorisation from someone legally able to act on the individual's behalf.

Insurers may sometimes seek to use the SAR provisions of UK GDPR to obtain full medical records. Advice from the Information Commissioner's Office is clear that SARs should not be used to access medical records for insurance purposes. We have separate guidance on this matter (see key resources).

Government departments

Government departments may request information about a patient, for example, to process claims for state benefits. The GMC advises doctors that they may accept an assurance from an officer of a government department or agency that the patient has given written consent to disclosure.

Police

A regular enquiry to the BMA is the right of access to health records by the police. If the police do not have a court order or warrant, they may ask for a patient's health record to be disclosed voluntarily under the Data Protection Act 2018. In such cases, healthcare professionals may only disclose information where the patient has given consent, or there is an overriding public interest in line with the criteria in section 8.7.



8.9

Family members and genetic information

The general principles of confidentiality apply equally to genetic information as to other information about health. Although genetic information frequently has relevance for family members, information about or provided by one patient should not be shared with others unless consent has been obtained (see section 8.3) or there is a legal requirement (see section 8.6) or an overriding public interest to justify disclosure (see section 8.7).

Complaints

When a patient complains about an episode of care, the matter cannot usually be investigated without some access to confidential information. Patients need to know this and should be told who will see the information, as well as being told about the safeguards in place. If they refuse to allow disclosure the complaint may not be able to progress, unless the information can be disclosed in the public interest (see section 8.7).

Patients sometimes involve their Member of Parliament (MP), or other elected representative, in the complaints process. Where the MP states in writing that they have the patient's consent for disclosure this may be accepted without further reference to the patient. Patients are also entitled to authorise relatives or carers to act on their behalf but, before responding, healthcare professionals should check that the patient consents to the disclosure.

When should information be withheld from access requests?

Certain information must not be disclosed when granting access to medical records. The most common examples are information which:

- is likely to cause serious physical or mental harm to the patient or another person; or
- relates to a third party who has not given consent for disclosure (where
 that third party is not a healthcare professional who has cared for the
 patient) and after taking into account the balance between the duty of
 confidentiality to the third party and the right of access of the applicant,
 the data controller concludes it is reasonable to withhold third party
 information.

The full list of exemptions and more detailed guidance on this topic can be found in our access to health records guidance.



Key resources

BMA – Access to health records

BMA – Focus on subject access requests for insurance purposes

GMC – Confidentiality: Disclosing information for employment,

insurance and similar purposes



Secondary uses of information

What are secondary uses?

Secondary uses of information (or indirect care uses) are activities which contribute to the effective provision of health and care services and benefit the population (or groups of patients) through the development of new treatments and service efficiencies. These activities fall outside the scope of primary use because they are not related to the direct care of the individual patient.

Examples of secondary uses include research, commissioning, health service management, risk stratification, financial and national clinical audit, and education.

Will anonymised or pseudonymised information suffice?

Disclosure of anonymised or pseudonymised data (see section 8.11) will often satisfy a number of secondary uses and must be used where practicable.

When is explicit consent needed?

Explicit patient consent is needed for the disclosure of confidential information for secondary purposes, unless one of the following applies.

- the disclosure has been granted support by the Health Research Authority's Confidentiality Advisory Group (CAG) under section 251 of the NHS Act 2006 (in England and Wales) (see below);
- it is a disclosure made under the Confidentiality and Disclosure of Information Directions 2013, which provide a limited statutory basis for some specific disclosures where it is not possible to obtain explicit consent and where it is not feasible to anonymise data. These specific disclosures relate to the financial and management arrangements of the NHS, for example quality and outcomes framework reviews and investigating complaints; or
- the disclosure is otherwise required by law, for example notification of an infectious disease (see section 8.6).

What is section 251 of the National Health Service Act 2006 (England and Wales)?

Regulations under section 251 of the NHS Act 2006 permit certain disclosures to occur without a breach of the common law duty of confidentiality.

The Health Service (Control of Patient Information, COPI) Regulations can provide statutory support to enable health service management and medical research when it is not practicable to obtain consent and anonymised information cannot be used. Disclosures under these regulations are commonly referred to as having 'section 251 support'.

When presented with a request for confidential information with evidence that it has 'section 251 support', healthcare professionals can disclose the relevant information. It is not a legal requirement to disclose, however disclosures are encouraged due to the public benefit they serve.

Those wishing to access confidential information with 'section 251 support' must apply to the independent Confidentiality Advisory Group of the Health Research Authority.

In rare situations when there is a risk to public health, for example in a pandemic, the Secretary of State for Health and Social Care can use the COPI regulations to require certain information to be shared to help manage and control the disease.



8.10

In Scotland, those wishing to access confidential information for purposes which support the delivery of healthcare must seek advice from the Public Benefit and Privacy Panel for Health and Social Care. In Northern Ireland, the Privacy Advisory Committee advises healthcare organisations about access to information relating to patients.

Can patients opt out of 'section 251' disclosures?

Yes. In all but rare circumstances, 'section 251 support' is granted with the condition that patients must be able to opt out of the disclosure. The rare circumstances when an opt-out may not apply is when there are public safety concerns or the disclosure is for emergency public health reasons.

The national data opt-out (where patients in England can register to opt out of their confidential information being used for research or planning purposes) applies to 'section 251' disclosures in addition to any local mechanisms for opting out.

The national data opt-out (England only)

Patients in England can register a national data out-opt (NDO) to prevent the use of confidential information for research or planning purposes (subject to certain exemptions). Patients can set their preferences <u>online</u>. Postal and phone options are also available.

The NDO does not apply to disclosures:

- which are required by law, for example certain disclosures to NHS England under the Health and Social Care Act 2012;
- for participation in national screening programmes;
- for monitoring and control of communicable disease and other risks to public health;
- where explicit consent for a specific project has been obtained from
- the patient; or
- which are authorised by a court order.

UK GDPR requirements

For disclosures of confidential information to be lawful it is necessary to comply with both the common law duty of confidence and UK GDPR. Healthcare professionals should note that if consent is being sought to meet the common law this may not reach UK GDPR requirements for explicit consent which are higher than the common law. Instead, where these higher standards are not met, UK GDPR provides valid alternative legal bases which should be used in preference to consent. (See our separate guidance on GPs as data controllers under GDPR.) All secondary uses of confidential information must comply with the UK GDPR principles, including the requirement for transparency and the use of privacy notices which explain how confidential information is used and shared.



Key resources

GMC – <u>Confidentiality</u>: <u>good practice in handling patient information</u> Health Research Authority – <u>GDPR Guidance for researchers and</u> <u>study co-ordinators</u>

NHS Digital – National data opt-out operational policy guidance



8.11

Anonymised and pseudonymised information

Disclosures of confidential information should be kept to the minimum necessary to achieve the purpose. Where possible, anonymised or pseudonymised information must be used if it will achieve the purpose of the disclosure.

A distinction must be drawn between anonymised information and pseudonymised information. There are important differences in how the two types of information can be disclosed.

Anonymised information

Information is anonymised if it does not identify individuals or does not enable individuals to be identified. The Information Commissioner's Office (ICO) says that if 'reasonably available' means can be used to re-identify individuals, that data will not have been effectively anonymised. A risk assessment of the means reasonably likely to identify an individual must be made considering the costs, time taken, and available technology. An example of anonymised data is national statistics which show the number of people attending A&E departments within a given time period.

When can anonymised information be disclosed?

'...disclosure by doctors or pharmacists to a third party of anonymous information, that is information from which the identity of patients may not be determined, does not constitute a breach of confidentiality.'

Rv Department of Health, ex parte Source Informatics Ltd (2001)

Anonymised information can be freely used or disclosed without consent, including publication. Before disclosing anonymised information, healthcare professionals must be confident that the information is truly anonymised. The removal of direct identifiers such as name, NHS Number (or CHI), date of birth, and postcode can still leave information identifiable in some circumstances for example, rare diseases, drug treatments, or statistical analyses which have very small numbers. A combination of items increases the chance of identification.

Pseudonymised information

Pseudonymisation is a common technique for de-identifying information. UK GDPR considers pseudonymised data to be personal data unless the organisation holding the data does not have access to separate information that allows the re-identification of individuals.

Information is pseudonymised when obvious identifiers such as name, NHS Number (or CHI), or date of birth have been removed and replaced with a unique code or pseudonym which is held separately. However, the information is still about an individual person which increases the risk of re-identification. It might be possible, for example, to re-identify individuals if access is given to the 'key' to reverse the code or pseudonym or by linking the pseudonymised information with other sources of data. Pseudonymised information must be subject to technical and organisational safeguards to reduce the risk of re-identification of individuals.



8.11

When can pseudonymised information be disclosed?

When considering a disclosure of pseudonymised information, the environment in which the information is to be disclosed is of critical importance. To minimise the risk of re-identification of individuals, pseudonymised information must remain within a secure and controlled environment which has technical restrictions and contractual controls, for example:

- governance of the re-identification 'key' including ensuring that those who have access to the pseudonymised information do not have access to the 'key';
- contractual prohibitions on attempts at re-identification or linking to other data;
- confidentiality clauses in staff contracts, including sanctions;
- limits on access to the pseudonymised information; and
- use of encryption processes.

This list is not exhaustive and a risk assessment must be conducted, and documented, in each case. Healthcare professionals should follow the ICO's code of practice on anonymisation when considering disclosing anonymised or pseudonymised information (see key resources). Specialist advice might be needed when assessing the level of risk of re-identification and what level of controls should be in place to mitigate the risk.

Who can anonymise information?

It is not a breach of confidentiality if information undergoes anonymisation or pseudonymisation processes within the direct care team for a purpose that would be within patients' reasonable expectations (see section 8.3).

A lawful justification (see section 8.1) is required if confidential information is to be disclosed to a third party outside of the direct care team in order to undergo anonymisation or pseudonymisation processes.



Key resources

ICO – Anonymisation: managing data protection risk code of practice Note that this guidance is out of date as it refers to the DPA 1998. The existing guidance should be followed while the updated version is awaited.



8.12

Security and avoiding inadvertent breaches

Keeping information secure

All healthcare professionals have obligations to handle confidential information responsibly and securely and protect it against improper access or disclosure. Protections are needed against both external threats such as cyberattacks and internal threats such as accidental or deliberate breaches by staff.

There are some data security responsibilities which lie at senior organisational level in NHS trusts, local authorities, or with GP data controllers, although this will vary depending on the size and type of organisation. Those responsible must ensure compliance with national technical security standards and updates of software to protect IT systems from cyber threats.

All healthcare staff should know the identity of their Caldicott Guardian, Data Protection Officer, or Senior Information Risk Owner and know how to report a data breach or near miss.

General principles

To minimise the risk of unauthorised access to confidential information all healthcare staff must:

- not access a patient's record without a legitimate reason;
- avoid conversations in public places which may disclose confidential information, including online forums and social media;
- have appropriate training in confidentiality and data security matters;
- query the status of strangers on the premises; and
- wear ID where issued.

Digital or electronic records

In the case of digital or electronic records healthcare professionals must:

- always log out of any computer system when work is finished;
- not leave a terminal unattended and logged in;
- not share passwords or Smartcards with others;
- always clear the screen of a previous patient's information before seeing another;
- follow local policies on taking laptops or other portable devices home or offsite; and
- follow local policies on the use encryption and password protection.

Manual or paper records

Manual records must be:

- held in secure storage such as locked filing cabinets;
- formally booked out from their normal filing system;
- tracked if transferred, with a note of their current location within the filing system;
- returned to the filing system as soon as possible after use;
- kept closed when not in use so that the contents are not seen by others;
- inaccessible to members of the public; and
- kept on site unless removal is essential.



8.12

Telephone calls

Healthcare staff should confirm the identity of telephone callers if doubt exists that the caller is who they say they are, for example, by calling them back using an independent source for the phone number. Messages should not be left on answering machines to which others may have access or with family members.

Recorded telephone conversations are confidential in the same way as other information disclosed by patients for the purposes of receiving healthcare. Patients should be informed if their call may be recorded.

Texting patients

Many patients prefer their healthcare professionals to use text messages as a convenient way of communicating with them. It is acceptable to use text messages to communicate with patients about their care, however, agreement should be sought from patients in advance that they are happy to receive communications in this way. Asking the patient to actively agree in advance to text messages can help to avoid misunderstandings or an inadvertent breach of confidentiality. Patients should be made aware of the types of information they can expect to receive by text, for example appointment reminders, repeat prescriptions or test results. The phone or device used to send the text messages must be secured in the same way as other electronic records to prevent accidental disclosure of the communication.

Emailing patients

The NHS requires that confidential information held in digital or electronic form is encrypted before transmission. Great care must be taken to ensure that the correct email address is used, and that emails sent to more than one patient at once are bcc'd so that no recipient can see any of the other recipients' names or email addresses. The ICO has specific guidance on email and security which covers the use of bcc.

Sending confidential information to an unencrypted email address is not secure therefore the BMA advises that patients should be made aware of, and accept, the risks. This can be achieved by asking the patient to sign a disclaimer which includes:

- a checklist so that the patient can specify the information they are happy for the practice to send by email, for example, appointment reminders, appointment cancellations, or test results. The practice must abide by the patient's instructions;
- confirmation of the email address that the patient has provided the
 practice is likely to be in breach of the UK GDPR if information is sent to
 the wrong email address;
- a statement that the patient is responsible for informing the practice of any change to their email address; and
- a statement that the patient is responsible for informing the practice of any change to their preferred method of communication, for example, if they no longer wish to receive information by email.



8.12

Processing and storing images

When remote consultations take place doctors can receive images, including intimate images, for clinical purposes. National guidance confirms that the approach to storing images should be the same as it would be for face-to-face interactions.



Key resources

DHNI – <u>Code of Practice on Protecting the Confidentiality of Service</u> <u>User Information</u>

NHS England – <u>Data Security and Protection Toolkit</u>
NHS Scotland – <u>How the NHS handles your personal health information</u>



Visual and audio images/recordings

The advice in this section makes a distinction between disclosing images/recordings made as part of a patient's care, and those made for non-patient care reasons, including with the intention of publication or broadcast.

When can recordings made as part of a patient's care be disclosed?

Visual and audio images/recordings made for clinical purposes are part of the medical record and are subject to the usual duty of confidentiality. These images can be shared for the direct care of a patient under implied consent (see section 8.3).

Adults with capacity

Images/recordings made as part of a patient's care should be treated in the same way as the rest of the medical record in terms of disclosures for secondary uses (see section 8.10), such as research or education and training. This means that explicit consent for disclosure will usually be required unless another lawful justification can be identified. Anonymised images can be disclosed for healthcare-related secondary uses, such as teaching or research, without consent. Those disclosing anonymised images, however, must be aware that apparently insignificant details may still be capable of identifying the patient and must be removed or redacted.

Healthcare professionals may wish to publish a recording of a patient which was made as part of their care. In these circumstances, explicit consent must be obtained if the patient is, or may be, identifiable. GMC guidance states that if the recording is anonymised, it is good practice to seek consent before publishing, bearing in mind the difficulties in ensuring that all the features of a recording that could identify the patient to any member of the public have been removed. Extreme care should be taken about the anonymity of such recordings before using or publishing them without consent in journals, other learning materials or any other media to which the public will have access.

The advice in earlier sections will apply when considering if disclosure of a recording is required by law (see section 8.6) the duty of confidentiality is set aside (see section 8.10) or the disclosure is justified in the public interest (see section 8.7).

The BMA has separate guidance on patients recording consultations (see key resources).

Adults lacking capacity

Medical research

If the image/recording cannot be anonymised, identifiable information can be disclosed for medical research provided it is in the best interests, or would benefit, the patient and is in line with relevant legislation. (Healthcare professionals should refer to the BMA's separate guidance on adults who lack capacity (see key resources) when considering disclosing identifiable information about adults lacking capacity for medical research.)



Education and training purposes

The law in relation to adults lacking capacity and the use of identifiable images/recordings for education and training purposes is untested. In the BMA's view it is difficult to see how such uses could be in the individual's best interests. Legal advice should be sought on a case-by-case basis for the use of identifiable images/recordings for reasons other than treatment and research.

When can recordings be made for use in widely accessible public media?

Publicly accessible media includes television, radio, online media and print.

Adults with capacity

The patient's explicit and written consent is required to make images/recordings intended for use in widely accessible public media. Explicit consent should still be sought even if it is considered that the patient is not identifiable, with the exception of certain intrinsically anonymous images, such as images of internal organs or images of pathology slides.

Patients should understand that, once material is published and in the public domain, it may be extremely difficult to withdraw it from circulation. Where a video recording has been made for a broadcast, doctors should check that patients understand that, once they have agreed to the recording being made for the broadcast, they may not be able to stop its subsequent use.

Adults lacking capacity

There are specific legal requirements in mental capacity legislation for making images/recordings of adults who lack capacity and using or disclosing such recordings. Legal advice should be sought in this area. The GMC states that in making audio or visual images/recordings for other secondary purposes, including images/recordings for publication, doctors must be satisfied that:

- the image/recording is necessary and benefits the patient or is in their best interests; and
- that the purpose cannot be achieved in a way that is less restrictive of the patient's rights and choices.



Key resources

BMA – <u>Adults with incapacity Scotland toolkit</u>

BMA – Mental Capacity Act Toolkit

BMA – Mental capacity in Northern Ireland toolkit

BMA – <u>Patients recording consultations</u>

GMC – Making and using audio and visual recordings of patients



Online complaints and the media

Responding to online complaints

Reading critical comments online from patients can be extremely upsetting and stressful. Many healthcare professionals feel strongly that patients forfeit their rights to confidentiality by posting on social media or speaking publicly and that they should be entitled to 'set the record straight' and correct any inaccuracies. In practice, healthcare professionals who do this would risk criticism and breach confidentiality. This principle applies even if the person replying to the complaint is not the member of staff complained about. Defending a colleague in a way that breaches confidentiality risks worsening the situation for both.

The advice of the GMC is that doctors should usually limit their public response to an explanation of the legal and professional duty of confidence that prevents them from commenting on specific cases, such as the one under discussion. This makes it clear that doctors do not have the right of reply and that readers should bear that in mind when reading the original complaint.

Any response must reflect the professionalism of healthcare staff. An inappropriate tone or impolite response may risk undermining public confidence in healthcare professionals.

Disclosures to the press

Under normal circumstances there will be no basis for disclosure of confidential information to the press. There will be occasions, however, when healthcare professionals are asked for information about individual patients.

For example, they may be asked to comment:

- on the condition of a celebrity patient. When the patient has the capacity
 to make decisions about disclosure, consent is essential before any
 information is released to the media. When the patient lacks capacity,
 legal advice should be sought; or
- after incidents involving harm to many people. During or after major disasters, for example a fire, road traffic accident, terrorist attack, or outbreak of infectious disease, it is important that requests for information are dealt with sensitively, while not breaching the confidentiality of patients.



Key resources

GMC – Responding to criticism in the media



Statutory restrictions on disclosure

Healthcare professionals are required by law to restrict the disclosure of some specific types of information. We have listed the most common examples below.

- The Gender Recognition Act 2004 (UK)
 Allows transgender people who have taken decisive steps to live fully and permanently in their acquired gender to apply for legal recognition of that gender. The Act makes it an offence to disclose 'protected information' (except in exceptional circumstances, for example, to comply with a court order) when that information is acquired in an official capacity. It defines 'protected information' as information about a person's application to the Gender Recognition Panel for gender recognition and a person's gender history after that person has changed gender under the Act.
- The Human Fertilisation and Embryology Act 1990 (UK)
 Protects confidentiality of the information kept by clinics and the Human Fertilsation and Embryology Authority (HFEA). Information can only be viewed by the clinic licence-holder and by staff or members of the HFEA (there are some additional limited exceptions to the restriction on disclosure, for example, disclosures to the Registrar General or a court). Disclosure of information which identifies the patient to another party without the patient's prior consent is a criminal offence. For more information see the HFEA's code of practice.



Additional BMA ethics and human rights guidance and resources

Additional BMA ethics and human rights guidance and resources

Abortion

Decriminalisation of abortion: a discussion paper from the BMA

How will abortion be regulated in the UK if criminal sanctions are removed?

The law and ethics of abortion

The removal of criminal sanctions for abortion: BMA position paper

Adults who lack capacity

Best interests decision making for adults who lack capacity toolkit (England and Wales)

<u>Clinically-assisted nutrition and hydration and adults who lack the capacity to consent</u>

Deprivation of liberty safeguards (England and Wales)

Needlestick injuries and blood-borne viruses

Taking blood specimens from incapacitated drivers

Children and young people

Non-therapeutic male circumcision toolkit Sexual offences and under 18-year-olds in Northern Ireland

Confidentiality and health records

Access to health records

GDPR privacy notices for **GP** practices

Giving patients access to medical reports

GPs as data controllers under GDPR

Requests for medical information from insurers

Retention of health records

The duty of confidentiality where it is known or suspected that a patient has unlawfully attempted to end their pregnancy

Consent and refusal

Consent in paternity testing

Detention settings

Forensic and secure environments ethics toolkit

 $\underline{\text{Health and human rights in immigration detention}}$

Solitary confinement and children and young people

The doctor's role in restraint in custodial settings

The doctor's role in the youth secure estate

Doctor-patient relationship

Patients recording consultations

Seeking information about patients online

End of life

Decisions relating to CPR (cardiopulmonary resuscitation)

Organ donation

Physician assisted dying

Responding to patient requests for assisted dying



Health and human rights

BMA human rights advocacy
Health and human rights in the new world (dis)order

Medical students

Ethics toolkit for medical students

Personal ethics

Ethics of social media use
Moral distress in the NHS and other organisations
The ethics of taking industrial action as a doctor
Transparency for doctors with competing interests

Refugees, overseas visitors, and vulnerable migrants

Access to healthcare for overseas visitors

BMA view on charging overseas visitors

Refugee and asylum seeker patient health toolkit

Safeguarding

Adults at risk, confidentiality and disclosure information
Adult safeguarding toolkit
Doctors' responsibility with anti-radicalisation strategy

War, conflict, and humanitarian emergencies

Ethics toolkit for armed forces doctors
Working in conflicts and emergencies toolkit



British Medical Association BMA House, Tavistock Square, London WC1H 9JP bma.org.uk

© British Medical Association, 2024

BMA 20230381