



Llywodraeth Cymru
Welsh Government

Guide to Consent for Examination or Treatment

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Introduction

1. Any health professional whether they are working for an NHS organisation in a hospital or providing treatment in the community or primary care setting, should know how to take valid consent for physical interventions and treatment. This document sets out the legal requirements for obtaining valid consent and gives guidance on the circumstances in which treatment may be given to a person who cannot give his or her valid consent. It replaces previous guidance issued in 2002 and 2008. In particular it gives guidance on the issue of **material** risk, which was highlighted in recent case law.
2. Healthcare professionals are advised to familiarise themselves with this document and with the consent policies of their own organisation, which should reflect this guidance.
3. It should be noted that the following areas are not included in this guidance:
 - participation in observational studies and
 - the use and sharing of personal information.
4. Standard 4.2 of the *Health and Care Standards for Wales*¹ requires healthcare organisations to ensure that valid consent is obtained in line with the law and best practice guidance. Healthcare Inspectorate Wales will assess compliance with this standard as part of its annual reviews of healthcare organisations.
5. This guidance reflects the Welsh Government's commitment to promoting equality of opportunity for all, whatever their race, language, religion or other belief, disability, age, gender and sexual orientation, to ensure that every citizen has the opportunity to make informed choices about their health care, and that compliance to equality legislation is met.

¹ <http://gov.wales/docs/dhss/publications/150402standardsen.pdf>

Chapter 1: Principles of Consent

6. Valid consent must be obtained before starting treatment, physical investigation or providing personal care for a patient. This principle reflects the right of a person to decide what happens to their own bodies and is a fundamental part of good practice. Any health professional or other member of the healthcare team who does not respect this principle may be liable both to legal action by the patient and action by their professional body. Employing bodies may also be liable for the actions of their staff.

Case law

7. Case law (“common law”) has established that touching a person without valid consent may constitute the civil or criminal offence of battery. Furthermore, if health professionals (or other healthcare staff) fail to obtain proper and informed consent and the person subsequently suffers harm as a result of treatment, this may be a factor in a claim of negligence against the health professional involved. Poor handling of the consent process may also result in complaints being made either through the NHS complaints procedure or to professional bodies.
8. This guidance covers case law on consent which has evolved significantly over the past two decades. Of particular relevance are the following cases:

- **Glass v United Kingdom²**
- **R (on the application of Burke) v General Medical Council³**
- **Montgomery v Lanarkshire Health Board⁴**
- **Jones v Royal Devon and Exeter NHS Foundation Trust⁵**

9. Health professionals must also remember they are under a duty to keep themselves informed of legal developments subsequent to this guidance and which may have a bearing on their practice and of any guidance issued by their regulatory/professional organisations. Legal advice should always be sought if there is any doubt about the legal validity of a proposed intervention. While much of the case law refers specifically to doctors, the same principles will apply to other healthcare staff involved in examining or treating patients.

² Glass v United Kingdom (Application No 61827/00) [2004] 102.

³ R (on the application of Burke) v General Medical Council [2005] EWCA Civ 1003.

⁴ Montgomery v Lanarkshire Health Board [2015] UKSC 11.

⁵ Jones v Royal Devon and Exeter Foundation Trust (Lawtel 22 September 2015).

Relevant legislation

10. The following pieces of legislation are of relevance in the area of consent:

The Human Rights Act 1998

11. The Human Rights Act 1998 came into force in October 2000, giving further effect in the UK to the rights enshrined in the European Convention on Human Rights. The main articles which are likely to be relevant in medical case law are:

- **Article 2** (protection of right to life),
- **Article 3** (prohibition of torture, inhuman or degrading treatment or punishment),
- **Article 5** (right to liberty and security),
- **Article 8** (right to respect for private and family life),
- **Article 9** (freedom of thought, conscience and religion),
- **Article 12** (right to marry and found a family) and
- **Article 14** (prohibition of discrimination in enjoyment of Convention rights).

12. All public authorities are required to act in accordance with the rights set out in the Human Rights Act and all statutes must be interpreted by the courts so far as possible in accordance with those rights.

The Mental Capacity Act 2005

13. The Mental Capacity Act 2005 applies in relation to decisions about the care or treatment of people who lack capacity to consent for themselves. Most of the provisions in the Act apply to people who are 16 years or over. The Act sets out statutory principles governing when and how a decision may be made on behalf of someone else. It also sets out the legal requirements for assessing whether a person lacks capacity to make decisions for themselves and contains a number of safeguards. The Act is supported by a Code of Practice⁶ which assists health professionals to put the Act into practice.

14. The Act was amended in 2007 to introduce safeguards for people who lack capacity and are detained in circumstances amounting to a deprivation of liberty.

⁶ www.gov.uk/government/publications/mental-capacity-act-code-of-practice

The Human Transplantation (Wales) Act 2013

15. The Human Transplantation (Wales) Act 2013 changed the way in which consent is given to organ and tissue donation in Wales for the purposes of transplantation. The Act provides that in the absence of express provision in relation to consent, consent will be deemed to have been given in most cases. This means that, after death, a person's consent will be deemed to have been given unless they had expressed a wish for or against donation. However, deemed consent does not apply to the under 18s, people who have not lived in Wales for at least 12 months before they died, and people who lack capacity to understand that consent could be deemed in the absence of express action being taken. In addition, in practice, people who cannot be identified or whose next of kin cannot be found will not be subject to deemed consent.

The Human Tissue Act 2004

16. The Human Tissue Act 2004 continues to apply to the removal, storage and use of human tissue for purposes other than transplantation.

The Mental Health Act 1983

17. The Mental Health Act 1983 sets out, among other things, the circumstances in which persons liable to be detained under that Act may be treated without consent.

Regulatory/professional bodies

18. The standards expected of healthcare professionals by their regulatory bodies may at times be higher than the minimum required by the law. Although this guidance focuses primarily on the legal position, it also refers to guidance issued by professional bodies. It should be noted that the legal requirements in negligence cases have historically been based on the standards set by the professions for their members, and hence where standards required by professional bodies are rising, it is likely that the legal standards will rise accordingly.

19. This guidance is intended to be complementary to guidance on ethics and good professional practice issued by regulatory bodies. In cases where there appears to be a conflict then health professionals should seek the advice of their medical defence organisation or legal adviser.

Chapter 2: Seeking Valid Consent

Valid consent

20. For consent to be valid, it must be given voluntarily by an appropriately informed person who has the capacity to consent to the intervention in question. The informed person may either be the person themselves, someone with parental responsibility where the person is under 18, a person who has authority under a Lasting Power of Attorney or a court appointed deputy.
21. Consent will not be legally valid if the person has not been given adequate information or where they are under the undue influence of another. Acquiescence where the person does not know what the intervention entails is not “consent”. Where a person does not have capacity to give consent, then treatment may be given providing it is given in accordance with the Mental Capacity Act 2005. Further details on all these areas are contained in the following chapters of this guidance.

Whether the person has capacity

22. The Mental Capacity Act 2005 applies in relation to determining whether a person has capacity to give their consent. It is a principle of the Act that a person is assumed to have capacity to make decisions for themselves unless it is established on the balance of probability that they do not.
23. The starting assumption must always be that a person has the capacity to make a decision, unless it can be established that they lack capacity. An assessment of a person’s capacity must be based on their ability to make a specific decision at the time it needs to be made, and not their ability to make a decisions in general.
24. A person lacks capacity if they:
- have an impairment or disturbance (for example a disability, or trauma, or the effect of drugs or alcohol) that affects the way their mind or brain works, and
 - that impairment or disturbance means that they are unable to make a specific decision at the time it needs to be made.
25. A person is unable to make a decision if they cannot:
- understand information about the decision to be made,
 - retain that information in their mind, or

- use or weigh that information as part of the decision-making process.
26. These three points should be applied together. If a person cannot do any of these three things, they will be treated as unable to make the decision.
 27. A fourth scenario also applies. A person is unable to make a decision if they cannot communicate their decision in any way (whether by talking, using sign language or any other means such as making simple muscle movements, blinking an eye or squeezing a hand. This will apply to very few people, but it does include people who are unconscious or in a coma.
 28. In all cases, it is important to take all possible steps to try to help people make a decision for themselves.
 29. A person's capacity to understand may be temporarily affected by factors such as confusion, panic, shock, fatigue, pain or medication. However in such circumstances it should not be assumed that they do not have capacity to consent. Where there is any doubt then the healthcare professional should assess the person's capacity for taking the decision in question. If the assessment is inconclusive, a second opinion should be obtained. Where there is serious disagreement about a person's capacity to make a particular decision, legal advice should be sought.
 30. Capacity should not be confused with a health professional's assessment of the reasonableness of the person's decision. The person is entitled to make a decision that may be perceived by others to be unwise or irrational provided they have capacity to do so. In ascertaining a person's capacity, the health professional must not make a judgement on the basis of the person's appearance or on any other aspects of his or her behaviour.
 31. The person might refuse consent because he or she does not believe the advice that he or she is being given. In these cases the professional must make further enquiries as to why the person does not believe that advice. The person may be refusing treatment because they have a poor relationship with the health professional and simply do not trust them, or may consider that the professional is not sufficiently senior to give the advice.
 32. Care should be taken not to underestimate the capacity of a person with a learning disability, or anyone else with an impairing condition. Many people with learning disabilities and other cognitive impairments have the capacity to consent if time is spent explaining the issues in language that is appropriate for them, using visual aids and signing if necessary.

33. Further information about assessing capacity can be found in the Mental Capacity Act 2005 Code of Practice⁷ and in the advice published by the British Medical Association⁸.

Communication issues

34. A person will not be deemed to lack capacity merely because they have a limited ability to communicate. Care should be taken not to underestimate the ability of a person to communicate, whatever their condition. In some cases it may be because English is not the person's first language. Health professionals should take all steps which are reasonable in the circumstances to facilitate communication, using interpreters or communication aids as appropriate and ensuring that the person feels at ease. In particular careful consideration should be given to the way in which information is explained or presented, with emphasis given to straightforward words and phrases. Jargon is to be avoided.

Welsh language and other languages

35. Organisations must consider how they deliver services in the form of an Active Offer which is a key element of the *More Than Just Words* strategic framework for Welsh Language services in health, social services and social care. In taking valid consent, health professionals are encouraged to discuss conditions and treatment options in Welsh, British Sign Language (BSL) or other language when this is the person's first language. The health professional must feel sufficiently confident in his or her ability to speak the language when seeking the person's consent to examination or treatment. LHBs and NHS Trusts must also ensure that that they comply with the relevant Welsh Language Schemes or Standards.
36. Where appropriate, those who know the person well, including their family, carers and staff from professional or voluntary support services, may be able to advise on the best ways to communicate.
37. Where sign language is the person's first language, arrangements should be made for a qualified BSL interpreter to be present. Where a family member or friend is used to communicate via sign language with the individual, it could place a burden on them to understand and interpret procedures that are often complicated. By using the services of a qualified BSL interpreter, health professionals may be more confident that the person has fully understood the procedures and potential risks involved when giving their consent. It also ensures that the person's wishes are properly communicated.

⁷ See note 6

⁸ www.bma.org.uk/advice/employment/ethics/mental-capacity/assessing-mental-capacity

Whether the consent is given voluntarily

38. To be valid, consent must be given voluntarily and freely, without pressure or undue influence being exerted on the person either to accept or refuse treatment.⁹ Such pressure can come from partners or family members as well as health or care professionals. Professionals should be alert to this possibility and where appropriate should arrange to see the person on their own, or with an independent advocate, to establish that the decision is truly theirs.
39. When people are being seen and treated in environments where involuntary detention may be an issue such as prisons and mental health hospitals, there is a potential for offers of treatment to be perceived coercively, whether or not this is the case. Coercion invalidates consent and care must be taken to ensure that the person makes a decision freely. Coercion should be distinguished from providing the person with appropriate reassurance concerning their treatment, or pointing out the potential benefits of treatment for their health. Withdrawal of any privileges or loss of remission of sentence for refusing consent, or using such matters to induce consent may invalidate consent, and are not acceptable. Consent that has been obtained by fraud will not be valid.¹⁰

Informed consent

40. To give valid consent, the person receiving treatment needs to understand the nature and purpose of the procedure. Any misrepresentation of these elements will invalidate consent.

The Montgomery Case – material risk

41. The Supreme Court in the *Montgomery*¹¹ case set out that health professionals are under a duty to take reasonable care to ensure that the person is aware of any material risks involved in the recommended treatment, and of any reasonable alternative or variant treatments. A risk is a 'material' one in this context if, in the circumstances of the particular case:

- a reasonable person in that person's position would be likely to attach significance to the risk, or

⁹ The need for consent to be given voluntarily and freely has long been a requirement of the law; see, for example, *Re T* [1992] and *Freeman v Home Office* (No 2) [1984]

¹⁰ *Appleton v Garrett* [1997] 8 Med LR 75.

¹¹ [2015] UKSC 11.

- the doctor is, or should be reasonably aware, that the particular person in front of him or her would be likely to attach significance to it.
42. The materiality or otherwise of the risk turns on the facts of each individual case and on the person's characteristics.
43. Following the *Montgomery* judgment, the only circumstances in which a healthcare professional is entitled to withhold from the person information about a risk is where the professional reasonably considers that its disclosure would be seriously detrimental to the person's health, or where doing so is necessary, for example where the person requires treatment urgently but is unconscious or otherwise unable to make a decision. This exception is a limited one which the courts will interpret restrictively.
44. In order to comply with the duty to provide information, health professionals are required to enter into dialogue with the person, the aim of which is to ensure that the person understands the seriousness of his or her condition, the anticipated benefits and risks to the specific individual of the proposed treatment, and any reasonable alternatives. This will assist in putting the person in a position to make an informed decision, but only if the information provided is comprehensible.
45. The General Medical Council gives guidance on the nature of this dialogue, by encouraging professionals to work in partnership with their patients, and to listen and respond to their concerns and preferences, and to give patients the information they want or need in a way they can understand.¹²
46. In this context, the use of patient information leaflets, including leaflets which are specially written to assist people with learning disabilities, assist health professionals to provide people with information about the risks involved in a particular course of treatment. Such leaflets allow people to review the information after the consultation, which may in itself prompt further questions of the health professional to more fully understand the treatment being proposed.
47. Importantly, however, health professionals must not regard the use of patient information leaflets as providing the person with all of the necessary information for the purpose of obtaining consent for examination or treatment. The obtaining of consent is a process, which involves effective communication and dialogue between the professional and the individual, and merely providing an information leaflet will not meet the practitioner's obligations. In some cases a person's consent may be obtained by post

¹² GMC, Good Medical Practice (2013)

and this gives them time to read and reflect on the consent form and information provided. However, any healthcare professional carrying out a procedure on an individual must ensure that, immediately before the procedure, the person has understood the information and any risks, and that they still give their consent. If the person has queries or concerns he or she must be given time to consider any additional information.

48. The need for health professionals to do more than merely provide the person with an information leaflet is summarised by the Supreme Court in its judgment in the *Montgomery* case. It provides that the 'duty is not therefore fulfilled by bombarding the patient with technical information which she cannot reasonably be expected to grasp, let alone by routinely demanding her signature on a consent form'.

49. Following the *Montgomery* judgment, when giving people advice about a proposed treatment, health professionals should:

- take extreme care in the taking of consent, which is even more crucial than ever;
- give careful and comprehensible warnings about all significant possible adverse outcomes, material risks and reasonable alternative treatments;
- ensure that warnings of, and discussions about, the material risks are properly recorded in the notes;
- invite the person to sign the relevant entry to confirm that he/she has been given information about the material risk, has understood them, and accepts the risk and
- make a full entry in the notes, preferably signed by the patient, if treatment is refused, including the reason when given.

50. The lower courts' approach to the issue of informed consent and the provision of information to patients, post the Supreme Court's judgment in the *Montgomery* case, is demonstrated in the following cases, albeit the case-law is still developing.

51. In the *Mrs A*¹³ case, the High Court held that the practitioner had not been negligent in not informing the person of a 1 in 1,000 risk that her child would be born disabled and there was no reason to suspect that the patient, or a reasonable person in the patient's position, would have attached any significance to a risk of this level. The risk was not therefore a 'material' one which needed to be disclosed to the patient. However, the

¹³ *Mrs A v East Kent Hospitals University NHS Foundation Trust* [2015] EWHC 1038

judge also noted that his finding would have differed had the evidence shown the risk to be between 1 per cent to 3 per cent.

52. In the *Spencer* case¹⁴, the High Court found that the Trust had breached its duty of care to the patient by failing to warn him of the dangers of deep vein thrombosis and pulmonary embolism during surgery for a right inguinal repair. The decision was arrived at partly because it was evident that the healthcare professionals were aware of the risk – they had provided the patient with pneumatic boots prior to surgery – but had otherwise failed to warn the patient of the dangers.

53. Finally, it is noted that the High Court held in the *Jones*¹⁵ case that a claimant's particulars of claim in a clinical negligence action which related to treatment that was provided before the *Montgomery* judgment could be amended so as to claim that a healthcare professional had breached a duty of care by failing to provide information about a material risk. This was despite the fact that the nurse would not have been in breach of her duty of care for failing to disclose the same risk under the test that was in operation before the *Montgomery* case. The *Jones* case may suggest that all applications may be treated in the same way, regardless of whether they relate to treatment provided pre-*Montgomery*.

When patients do not wish to know

54. Some people may wish to know very little about the treatment which is being proposed and may ask that the health professional or other person should make decisions on their behalf. The Supreme Court confirmed in the *Montgomery* case that a healthcare professional is not obliged to discuss the risks inherent in treatment with a person who makes it clear that he or she would prefer not to discuss the matter. In such circumstances, the health professional should explain the importance of knowing about the treatment and try to encourage the patient to make the decisions for him or herself. However if the person still declines any information offered, it is essential to record this fact in the notes, and to ask the patient to sign the record to confirm their decision. It is possible that the person's wishes may change over time, and it is important to provide opportunities for them to express this. The GMC guidance encourages doctors to explain to patients the importance of knowing the options open to them, and states that basic information should always be provided. If a patient asks a doctor about the risk, then the doctor must give an honest answer.¹⁶

Additional procedures

¹⁴ *Spencer v Hillingdon Hospital NHS Trust* [2015] EWHC 1058

¹⁵ *Jones v Royal Wolverhampton Hospitals NHS Trust* [2015] EWHC 2154 (QB)

¹⁶ *Pearce v United Bristol Healthcare NHS Trust* [1999] 1 PIQR 53.

55. Where a patient is under anaesthetic, it may become evident that they could benefit from an additional procedure. If it would be unreasonable to delay the procedure until the person regains consciousness (for example, because there is a threat to the person's life), it may be justified to perform the procedure on the grounds that it is in the patient's best interests. This is confirmed by the Supreme Court's judgment in the *Montgomery* case.
56. The health professional should do no more than is reasonably required, in the best interests of the patient before he or she recovers consciousness. The patient should be informed if any additional procedure has been necessary as soon as he or she recovers consciousness. A major procedure such as a hysterectomy should never be performed during an operation without explicit consent, unless it is necessary to do so to save life¹⁷.
57. Health professionals should so far as possible try to anticipate additional procedures that may be necessary if certain circumstances arise and discuss these possibilities with the patient. He or she should consider the person's views and that they may need time to think or discuss with family or friends. The views of the patient should be noted on the consent form. If a person refuses certain additional procedures before the anaesthetic, then this must be respected if the refusal is applicable to the circumstances (see below for further information about advance decisions).

Use of removed tissue, including transplantation

58. The Human Transplantation (Wales) Act 2013 regulates in Wales consent to the removal, storage and use of human tissue from deceased or living donors, only for the purposes of transplantation. The Human Transplantation (Wales) Act 2013 changed the way in which consent is given to organ and tissue donation for the purposes of transplantation. The Act provides that in the absence of express provision in relation to consent, consent will be deemed to have been given in most cases. This means that, after death, a person's consent will be deemed to have been given unless they had expressed a wish for or against donation. However, deemed consent does not apply to the under 18s, people who have not lived in Wales for at least 12 months before they died, and people who lack capacity to understand that consent could be deemed in the absence of express action being taken. In addition, in practice people who cannot be identified or whose next of kin cannot be found will not be subject to

¹⁷ Re F (Mental Patient: Sterilisation) [1990] 2 AC 1.

deemed consent. The Human Tissue Authority has produced a code of practice covering the operation of the 2013 Act.¹⁸

59. In cases of living donation, express consent is always required from the donor. The only exception to this is where the donor cannot give consent, for example, because they lack capacity but it would be in their best interests to donate. Such cases would be extremely rare and may need the approval of the court. Legal advice should be sought. Where it is proposed that a transplant is to be undertaken where the individuals are genetically related, the potential donor may feel under considerable emotional pressure to help their sick relative. Before taking any steps, it is important that the health professional, having regard to the guidance issued by the Human Tissue Authority referred to above, ensures that the potential donor is giving consent freely and not because they feel under undue pressure to do so. The position of child bone marrow donors is covered in more detail in Chapter 5 below.
60. The Human Tissue Act 2004 continues to apply to the removal, storage and use of human tissue for purposes other than transplantation. The Act makes consent the fundamental principle for the removal, storage and use of human tissue. This includes material that has come from a human, including human cells. Cell lines are excluded as is hair and nail from living patients. It also covers the removal of such material from the deceased. Live gametes and embryos are excluded as they are regulated under the Human Fertilisation and Embryology Act 1990.
61. The 2004 Act lists the purposes for which consent is required. Consent must be given by an appropriate person, as defined in the Act, and penalties of up to three years imprisonment or a fine, or both, can be imposed for failure to obtain or misuse of consent. Full details about the requirements of the Human Tissue Act 2004 and the related codes of practice are on website of the Human Tissue Authority¹⁹.

Attendance by students and trainees

62. Where a student or trainee health professional is undertaking examination or treatment of the patient where the procedure will further the person's care – for example taking a blood sample for testing – then, assuming the student is appropriately trained in the procedure, the fact that it is carried out by a student does not alter the nature and purpose of the procedure. It is therefore not a legal requirement to tell the patient that the health

¹⁸ <https://www.hta.gov.uk/guidance-professionals/codes-practice/code-practice-10-human-transplantation-wales-act>

¹⁹ www.hta.gov.uk

professional is a student, although it would always be good practice to do so and consent in the usual way will still be required.

63. In contrast, where a student proposes to conduct a physical examination which is not part of the person's care, then it is essential to explain that the purpose of the examination is to further the student's training and to seek consent for that to take place. Again, consent should be recorded in the patient's notes.
64. A person's explicit consent should be obtained prior to any occasion when a student or trainee is going to be present during an examination or when treatment is to be given. People have the right to refuse consent in these circumstances without any detrimental effect on their treatment. Written consent must be obtained if students or trainees are going to be present during examination or treatment using sedation or anaesthetic.

Consent to video recordings and clinical photography

65. Video recordings of treatment may be used both as a medical record or treatment aid in themselves, and as a tool for teaching, audit or research. The purpose and possible future use of the video must be clearly explained to the person, before their consent is sought for the recording to be made. If the video is to be used for teaching, audit or research, patients must be aware that they can refuse without their care being compromised and that when required or appropriate the video can be anonymised. The same principles apply to clinical photography.
66. Occasionally, video recordings, clinical photography and /or radiographs may be required following injuries sustained as the result of an accident or an assault. Health professionals should be satisfied that the person has been given sufficient information for valid consent, making it clear that the recording could be used during legal proceedings, as part of a medical record, or possibly as a tool for teaching, audit or research.
67. The GMC guidance²⁰ gives detailed advice in the use of recordings when treating or assessing patients.

Who should seek consent

68. The health professional giving the treatment or carrying out the intervention is responsible for ensuring that the person has given valid consent before treatment begins. The GMC guidance states that the task of seeking consent may be delegated to another health professional, as long as that professional is suitably trained and qualified. In particular, they must have sufficient knowledge of the proposed investigation or treatment,

²⁰ GMC Making and Using Visual and Audio Records of Patients, April 2011

and understand the risks involved in order to be able to provide information about the treatment or procedure to the patient and discuss the risks. Inappropriate delegation (for example where the health professional seeking consent has inadequate knowledge of the procedure) may mean that the “consent” obtained is not valid. Health professionals are responsible for knowing the limits of their own competence and should seek the advice of appropriate colleagues when necessary.

When consent should be sought

69. The seeking and giving of consent is usually a process, rather than a one-off event. It is good practice where possible to seek the person's consent to the proposed procedure well in advance, when there is time to respond to questions and provide adequate information. Healthcare professionals should then check, before the procedure starts, that the person still consents. If a patient is not asked to signify their consent until just before the procedure is due to start, at a time when they may be feeling particularly vulnerable, there may be real doubt as to its validity. In no circumstances should patients be given routine pre-operative medication before being asked for their consent to proceed with the treatment.

Form of consent

70. The validity of consent does not depend on the form in which it is given and it can either be given in writing on a form or given verbally. Written consent merely serves as evidence of consent: the fact that a patient signed a consent form will not be valid consent if the patient does not have capacity, has not been given adequate information or is under undue pressure or influence.

71. Although completion of a consent form is in most cases not a legal requirement (exceptions include certain requirements of the *Mental Health Act 1983* and of the *Human Fertilisation and Embryology Act 1990*), the use of such forms is good practice where an intervention such as surgery is to be undertaken. Where there is any doubt about the person's capacity, it is important, *before* they are asked to sign the form, to establish both that they have the capacity to consent to the intervention and that they have received enough information to enable valid consent to be given. Details of the assessment of capacity, and the conclusion reached, should be recorded in the case notes.

72. Whilst obtaining the person's written consent is considered to be good practice in particular situations, for many procedures, particularly in a primary care setting, verbal consent will be adequate. However it is good practice for it to be given expressly by the patient rather than implied through their actions and for the consent to be noted in the medical record.

For interventions in primary care settings such as minor surgery, minor oral surgery and any other advanced forms of treatment such as pupil dilation, or treatment using local anaesthesia or sedation is to be undertaken, written consent should be obtained as a matter of good practice.

73. If the person has capacity, but cannot read or write, they may be able to make their mark on the form to indicate consent. It would be good practice for the mark to be witnessed by a person other than the clinician seeking consent, and for the fact that the person has chosen to make their mark in this way to be recorded in the case notes. Similarly, if the person has capacity, and wishes to give consent, but is physically unable to mark the form, this should be recorded in the notes. The person can direct someone to sign on their behalf but there is no legal requirement for them to do so. If consent has been validly given, the lack of a completed form is no bar to treatment.

Requirements concerning gametes

74. It is a legal requirement under the *Human Fertilisation and Embryology Act 1990* (as amended by the *Human Fertilisation and Embryology Act 2008*) that consent must be obtained in writing before a person's gametes can be used for the treatment of others or to create an embryo in vitro. Consent in writing is also required for the storage of gametes. Information and an opportunity to receive counselling must be provided before consent is given. Where these requirements are not satisfied, it is unlawful to store or use the person's gametes. Health professionals should ensure that written consent to storage exists before retrieving gametes.
75. Outside specialist infertility practice, these requirements may be relevant to health professionals whose patients are about to undergo treatment which may render them sterile (such as chemotherapy or radiotherapy) where a patient may wish to have gametes, or ovarian or testicular tissue, stored prior to the procedure. Health professionals may also receive requests to remove gametes from a person unable to give consent.

Research and innovative treatment

76. The same legal principles apply when seeking consent from people for research purposes as when seeking consent for investigations or treatment. However, in acknowledgement of the fact that research may not have direct benefits for the patients involved, particular care should be taken to ensure that possible research subjects have the fullest possible information, including on the material risks, about the proposed study and sufficient time to absorb it. Patients should never feel pressurised to take part, and advice must be given that they can withdraw from the research

project at any time, without their care being affected. If patients are being offered the opportunity to participate in a clinical trial, they should have clear information on the nature of the trial and the research must be carried out in accordance with the Medicines for Human Use (Clinical Trials) Regulations 2004²¹.

77. If the treatment being offered is of an experimental nature, but not actually part of a research trial, this fact must be clearly explained to patients before their consent is sought, along with information about standard alternatives. It is good practice to give people information about the evidence to date of the effectiveness of the new treatment, both at national/international level and in the practitioner's own experience, including information about known possible side-effects.
78. Where a person does not have capacity to consent then it will be unlawful to carry out research or experimental treatment unless it is in the patient's best interests.

Duration of consent

79. When a person gives valid consent to an intervention, in general that consent remains valid for an indefinite duration unless it is withdrawn by the patient. However, if new information becomes available regarding the proposed intervention (for example new evidence of risks or new treatment options) between the time when consent was sought and when the intervention is undertaken, the healthcare professional should inform the patient and reconfirm their consent. Similarly, if the patient's condition has changed significantly in the intervening time, it may be necessary to seek consent again, on the basis that the likely benefits and/or risks of the intervention may also have changed.
80. If consent has been obtained a significant time before undertaking the intervention, it is good practice to confirm that the person who has given consent (assuming he or she retains capacity) still wishes the intervention to proceed even if no new information needs to be provided or further questions answered.

²¹ Medicines for Human Use (Clinical Trials) Regulations 2004, SI 2004/1031, www.legislation.gov.uk.

Chapter 3: People who refuse treatment

Right to refuse treatment

81.If an adult with capacity makes a voluntary and appropriately informed decision to refuse treatment this decision must be respected, (except in certain circumstances as defined by the Mental Health Act 1983 (see below)). Any attempt to treat that patient against his or her wishes could amount to a criminal offence. It is the right of an adult patient with capacity to refuse treatment even if that refusal might result in the death of the patient.

82.However in cases of doubt or where refusal leads to serious consequences for the patient, health professionals should always refer the matter to their legal advisers who may advise that a declaration from the court should be sought. In the case of *Re T (Adult Refusal of Treatment)* 1993²² the court said that:

“if in a potentially life threatening situation or one where irreparable damage to the patient’s health is to be anticipated, doctors or health authorities are faced with a refusal by an adult patient to accept essential treatment and they have real doubts as to the validity of that refusal, they should in the public interest, not to mention that of the patient, at once seek a declaration from the courts as to whether the proposed treatment would or would not be lawful. The step should not be left to the patient’s family, who will probably not know of the facility and may be inhibited by questions of expense. Such cases will be rare, but when they do arise the courts can and will provide immediate assistance”.

83.Whilst a patient has the right to refuse treatment this does not mean that they have the right to insist on a particular course of treatment. (See paragraph 139 on *Burke v GMC*).

Treatment given under the Mental Health Act 1983

84.Where a patient is capable of giving consent and refuses, that patient may only be given medical treatment if it is for a mental disorder and the health professional has legal authority to give that treatment in accordance with Part 4 of the Mental Health Act 1983²³. Treatment for a mental disorder means any treatment the purpose of which is to alleviate, or prevent a worsening of, the disorder or one or more of its symptoms or manifestations. However the courts have extended the scope to include “a

²² *Re T (Adult Refusal of Treatment)* [1993] Fam 95, see Lord Donaldson.

²³ Part 4A of the Mental Health Act 1983 was inserted by the Mental Health Act 2007.

range of acts ancillary to the core treatment”²⁴. For example the courts have held that force feeding by naso-gastric tube of a patient with anorexia nervosa is a treatment for the symptom of that disorder. Any such treatment must, however, be justified not only as being in the patient’s best interests but also “convincingly” shown to be a “medical necessity”²⁵.

85. Treatment of an adult patient who is detained under the Mental Health Act for an unconnected ailment or condition will require consent if that patient is deemed to have capacity. In the case of *Re: C (Adult: Refusal of Treatment)*²⁶ a patient diagnosed as a chronic paranoid schizophrenic refused consent to the amputation of his gangrenous leg. The Court held that the patient had capacity to understand the nature, purpose and effects of the treatment advised, and consequently his right of self-determination had not been displaced even though he was a patient detained under the Mental Health Act. In this case the Court found that the treatment for the patient’s leg was unrelated to this mental disorder although health professionals should exercise extreme caution in such cases and seek legal advice. In this case, if the cause of gangrene had been as a result of the patient inflicting injury to his leg because of his mental disorder, then it is likely that any treatment would be considered as treatment for a symptom of the disorder.

86. Further information about consent and the Mental Health Act 1983 (as amended by the Mental Health Act 2007 and other statutes) is in the Mental Health Act Code of Practice for Wales.²⁷

Other Exceptions

87. The Public Health (Control of Disease) Act 1984 provides that, subject to an order made by a magistrate, persons suffering from certain notifiable infectious diseases can be medically examined, removed to, and detained in a hospital without their consent.²⁸

Medical treatment and an unborn child

88. If an adult woman with capacity is pregnant and refuses treatment, the courts have made it clear that even if refusal of treatment amounts to adverse consequences for the foetus, health professionals cannot intervene.²⁹ Medical intervention can only be taken if it is believed that the

²⁴ *B v Croydon HA* [1995] 1 All ER 683 (CA).

²⁵ *Herczegfalvy v Austria* (1993) 15 EHRR 437 (ECtHR) applied in *R (on the application of Wilkinson) v Broadmoor Special Hospital Authority* [2002] 1 WLR (CA) and *R (on the application of N) v M* [2003] 1 WLR 562 (CA).

²⁶ [1994] 1 WLR 290.

²⁷ Mental Health Act 1983: Code of Practice for Wales, Welsh Government, June 2016.

²⁸ As amended by the Health and Social Care Act 2008

²⁹ *Re MB (Medical Treatment)* [1997] 2 FLR 426.

patient lacks capacity to consent (see Chapter 4).³⁰ However where a refusal leads to serious consequences for the patient or her unborn child and/or there is any doubt as to her capacity, then legal advice should be obtained.

Withdrawal of consent

89. A person with capacity is entitled to withdraw consent at any time, including during the performance of a procedure. Where a patient does object during treatment, it is good practice for the health professional, if at all possible, to stop the procedure, establish the patient's concerns, and explain the consequences of not completing the procedure. At times an apparent objection may reflect a cry of pain rather than withdrawal of consent, and appropriate reassurance may enable the health professional to continue with the patient's consent. If stopping the procedure at that point would genuinely put the life of the patient at immediate risk, and the health professional believes that the patient is unable to understand the implications of their objection, this may be because the patient temporarily lacks capacity as a result of the pain. In this case the health professional may continue until the risk no longer applies but only while the patient lacks capacity.

Advance statements

90. A patient with capacity may make a statement setting out their wishes concerning their future health care in the event that they no longer have capacity (previously referred to as "living wills" or "advance directives"). A valid and applicable advance decision to refuse treatment has the same force as a contemporaneous decision to refuse treatment.

Advance decisions to refuse treatment

91. The Mental Capacity Act 2005 puts advance decisions on a statutory footing. The Act sets out the requirements that such a decision must meet to be valid and applicable. In summary these are:

- the person must be 18 or over;
- the person must have capacity to make the decision;
- the person must make clear which treatments they are refusing;
- if the advance decision refuses life-sustaining treatment, it must be in writing (it can be written by someone else or recorded in notes), it

³⁰ Attorney General's Reference (No 3 of 1994) [1997] 3 WLR 421; and Re MB (Medical Treatment) [1997] 2 FLR 426.

must be signed and witnessed and it must state clearly that the decision applies even if life is at risk;

- a person with capacity can withdraw their advance decision at any time.

92. Healthcare professionals must follow an advance decision if it is valid and applicable, even if it may result in the person's death. If they do not, they could face criminal prosecution or civil liability. The Mental Capacity Act 2005 protects a health professional from liability for treating or continuing to treat a person in the person's best interests if they are not satisfied that an advance decision exists which is valid and applicable. The Act also protects healthcare professionals from liability for the consequences of withholding or withdrawing a treatment if at the time they reasonably believe that there is a valid and applicable advance decision.

93. If there is genuine doubt or disagreement about an advance decision's existence, validity or applicability, the case should be referred to the Court of Protection. The court does not have the power to overturn a valid and applicable advance decision. While a decision is awaited from the courts, healthcare professionals can provide life-sustaining treatment or treatment to stop a serious deterioration in the patient's condition. If an advance decision is not valid or applicable to current circumstances, healthcare professionals must consider the advance decision as part of their assessment of the person's best interests. Advance decisions made before the Mental Capacity Act came into force may still be valid if they meet the provisions of the Act. There are transitional arrangements for advance decisions to refuse life-sustaining treatment made before 1 October 2007.

94. Some healthcare professionals may disagree in principle with a person's right to refuse life-sustaining treatment. The Mental Capacity Act does not change the current legal position. Healthcare professionals do not have to act in a way that goes against their beliefs; however, they must not simply abandon patients or cause their care to suffer. A patient should have the option of transferring their care to another healthcare professional or, if the patient lacks capacity, arrangements should be made for the management of the patient's care to be transferred to another healthcare professional.³¹

95. Patients should always be offered measures that are essential to keeping them comfortable.³² This is sometimes referred to as 'basic' or 'essential' care, and includes warmth, shelter, actions to keep a person clean and free from distress and the offer of food and water by mouth. The BMA's

³¹ Re B (adult: refusal of medical treatment) [2002] EWHC (Fam)

³² BMA (2007) Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for decision-making (third edition)

guidance advises that basic care should always be provided unless it is actively resisted by a patient, and that 'refusals of basic care by patients with capacity should be respected, although it should be continued to be offered'. Advance decisions made under the Mental Capacity Act cannot refuse actions that are needed to keep a person comfortable. The Act allows healthcare professionals to carry out these actions in the best interests of a person who lacks capacity. An advance decision can refuse artificial nutrition and hydration.

96. However, although basic/essential care would include the offer of oral nutrition and hydration, it would not cover force feeding an individual or the use of artificial nutrition and hydration. The courts have recognised that an individual with capacity has the right to choose to refuse food and drink, although this may be qualified if the person has a mental disorder. Towards the end of such a period an individual is likely to lose capacity, and the courts have stated that if the individual has, while they have capacity, expressed the desire to refuse food until death supervenes, the person cannot be force fed or fed artificially when they lack capacity. If the person is refusing food as a result of mental disorder, then detention and treatment without consent may be a possibility under the Mental Health Act 1983, different considerations may apply and more specialist guidance should be consulted.³³

Other types of advance statements

97. If an advance statement has been made that is not valid and applicable under the Mental Capacity Act 2005, this does not mean that the statement can be ignored. It should at least be noted as an expression of the person's feelings and wishes about what should happen to them if they lack capacity to decide for themselves, and should be taken into account in deciding what is in their best interests.
98. As well as an advance statement to refuse treatment, some statements will express the person's wishes that a particular course of action should be taken or that they should receive a particular type of treatment in the event that they no longer have capacity. Whilst a health professional may have a legal duty to his or her patient, he or she is not under a legal obligation to provide treatment because the patient demands it. The decision to treat is ultimately a matter for his or her professional judgement acting in the person's interests.³⁴ In making that decision the health professional will, however, be required to take into account the patient's wishes as expressed in determining what is in his or her best interests.

³³ Mental Health Act Commission (1979) Guidance Note 3: Guidance on the treatment of anorexia nervosa under the Mental Health Act 1983 (updated March 1999)

³⁴ R (on the application of Burke) v General Medical Council [2005] EWCA Civ 1003.

Self-harm and attempted suicide

99. Cases of self-harm present a particular difficulty for health professionals but the same law and guidance, as set out above, applies to treatment of these cases. Where the patient is able to communicate, an assessment of their mental capacity should be made as a matter of urgency. If the patient is judged not to have capacity, they may be treated in accordance with the Mental Capacity Act 2005. If a patient has attempted suicide and is unconscious, he or she should be given emergency treatment unless the health professional is aware of any valid and applicable advance decision to refuse life-sustaining treatment in these circumstances.
100. However, as noted above, unless one of the statutory exceptions apply, adult patients with capacity do have the right to refuse life-sustaining treatment, both at the time it is offered and in the future even if the health professional believes that the patient's decision is unwise or irrational. If a patient with capacity has harmed themselves and refuses treatment, a psychiatric assessment should be obtained. Unless the adult patient with capacity is detained under the Mental Health Act 1983 and the treatment is for, or a symptom of, a mental disorder, then their refusal must be respected although clearly attempts should be made to encourage him or her to accept help and health professionals should consult legal advisers.

Chapter 4: Adults who lack capacity

General principles

101. Where an adult patient lacks capacity to give his or her consent to treatment, no one can give consent for that person unless they have authority under a Lasting Power of Attorney or have been authorised to make treatment decisions as a deputy appointed by the Court. However, decisions still need to be made about the person's care and treatment. Since October 2007, the Mental Capacity Act 2005 ("the Act") has provided a statutory basis on which treatment may be given to patients who are 16 years or above and lack capacity, and sets out general principles which must be applied. These principles are as follows:

- a person must be assumed to have capacity unless it is established that he or she lacks capacity;
- a person is not to be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success;
- a person is not to be treated as unable to make a decision merely because he or she makes an unwise decision;
- an act done, or decision made, under the Act for or on behalf of a person who lacks capacity must be done, or made, in his or her best interests;
- before the act is done, or the decision is made, regard must be had to whether the purpose of which it is needed can be effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

102. The Act sets out the circumstances in which decisions may be made on behalf of a person and makes it an offence to ill-treat or neglect them. Detailed guidance is provided in the Mental Capacity Act Code of Practice³⁵ and any person engaged in the care and treatment of an adult who lacks capacity must have regard to this Code.

103. The Act provides that any treatment of an adult who lacks capacity will be lawful, provided that the professional reasonably believes that the patient lacks capacity to make a decision in relation to the matter, and the treatment proposed is in the patient's best interests. As with the common law, they are required to assess whether the patient has capacity and, if

³⁵ See Ministry of Justice website.

not, whether the treatment proposed is in their best interests. Determining a patient's capacity is covered in Chapter 2 above.

Best interests

104. In determining what is in the person's best interests, the health professional must look at their circumstances as a whole and not just at what is in their best medical interests. They must try to ascertain what the patient would have wanted if he or she had capacity, rather than what that professional believes to be in his or her best interests. The professional must consider:

- the person's past and present wishes and feelings,
- the beliefs and values that would be likely to influence their decision if they had capacity, and
- any other factors that the patient might think relevant.

105. They must also, so far as it is practicable and appropriate to consult them, take account of the views of the following people:

- anyone named by the patient as a person who should be consulted on such matters;
- anyone engaged in caring for the person or interested in his welfare;
- a person who has been granted a Lasting Power of Attorney by the patient; and
- any deputy appointed for the patient by the Court.

106. The purpose of consulting is to ascertain what the patient would have wanted if they had capacity, and not what the persons consulted believe should happen. Where a patient has made a Lasting Power of Attorney or a deputy of the Court has been appointed, then if it is within their authority, it may be for the attorney or deputy to make the decision on the patient's behalf. However, they too must act in the patient's best interests and, where practicable and appropriate, all of the above named people must still be consulted.

107. Lack of capacity will not automatically mean that the person is unable to participate in the decision making process, and every assistance should be given to enable him or her to do so.

108. If a person has no one who may be consulted then health professionals must consider whether the circumstances are such that an Independent Mental Capacity Advocate (IMCA) should be instructed.

109. Where a patient has made an advance statement then this will be relevant in deciding what is in the patient's interests. If it is a valid and applicable advance decision made under the Mental Capacity Act, then the question of what is in the patient's best interests is irrelevant and the patient's refusal of treatment is binding on the health professional unless treatment may be provided under a statutory exception. If the patient has made an advance statement not valid and applicable in accordance with the Act, then the health professional should still take that statement into account in deciding what is in the patient's interests. However, if it is the health professional's clinical judgement that to act in accordance with the advance statement would not be in the patient's best interests, he or she is not bound where the advance statement is not a valid and applicable advance decision.

Temporary incapacity

110. The provisions of the Mental Capacity Act 2005 apply to acts or decision made on behalf of an adult who lacks capacity – whether the lack of capacity is likely to be temporary or permanent. Patients may suffer a temporary lack of capacity, for example, where they are under a general anaesthetic or sedation, or unconscious after a road accident. In order to save the person's life or to prevent serious harm, it will almost always be in the person's best interests to give urgent treatment without delay, unless the patient has a valid and applicable advance decision to refuse treatment. If a medical intervention is thought to be in the patient's best interests but can be delayed until the patient recovers capacity and is able to consent to (or refuse) the intervention, it must be delayed until that time.

Fluctuating capacity

111. It is possible for capacity to fluctuate. In such cases, it is good practice to establish whilst the person has capacity their views about any assessment, treatment and care that may be necessary during a period of incapacity and to record these views. The person may wish to make an advance decision to refuse certain types of treatment. If the person does not make any relevant advance decision, the person's treatment when incapacitated should be determined in the usual way, by following the Mental Capacity Act 2005.

Lasting Power of Attorney

112. The Mental Capacity Act enables a person aged 18 or over to appoint an attorney to make health and welfare decisions on their behalf should they lack the capacity to make such decisions in the future. A Lasting Power of Attorney ("an LPA") must meet the various legal requirements set

out in the relevant regulations³⁶ and must be registered with the Office of the Public Guardian before it can be used.

113. An LPA does not, however, authorise an attorney to refuse or give consent to life-sustaining treatment unless this is specifically expressed in the instrument that creates the LPA.
114. If two or more people have been appointed as attorneys, then they may either be appointed to act jointly or jointly and severally. If they are acting jointly then any decision must be by consensus. However if they are acting jointly or severally, then either of the attorneys can make a decision independently of the other. If it is not clear how the attorneys have been appointed, then it is assumed that they are appointed to act jointly.
115. If the person has made a valid and applicable advance decision to refuse treatment, then this can be overridden by an attorney providing that his or her authority extends to making decisions about treatment that is the subject of the advance decision. An attorney, like any person who is making a decision on behalf of a person who lacks capacity, must act in accordance with the Act and must have regard to the Code of Practice.³⁷
116. When acting on the basis of a decision by an attorney, a health professional should, so far as is reasonable, try to ensure that the attorney is acting within their authority. If there are any disputes between a health professional and an attorney that cannot be resolved, or where there are grounds for believing that the attorney is not acting in the patient's best interests, legal advice should be sought.

Independent Mental Capacity Advocates

117. Under the Mental Capacity Act 2005, an independent mental capacity advocate ("an IMCA")³⁸ *must* be instructed, and then consulted, for people lacking capacity who have no-one else to support them (other than paid staff), where an NHS body is proposing to provide serious medical treatment. There are other circumstances in which an IMCA must be appointed such as decisions about long-term accommodation. Further information about IMCAs is given in the Mental Capacity Act 2005 Code of Practice.
118. Serious medical treatment for this purpose means treatment which involves providing, withdrawing or withholding treatment in circumstances:

³⁶ Mental Capacity Act 2005 (Lasting Power of Attorney, Enduring Powers of Attorney and Public Guardian) Regulations 2007 (S.I.2007/2161), see also www.publicguardian.gov.uk

³⁷ See note 6

³⁸ The statutory duty to instruct an IMCA is contained in the Mental Capacity Act 2005 and the Mental Capacity Act 2005 (Independent Mental Capacity Advocates) (Wales) Regulations 2007 (S.I. 2007/852 (W.77)); see www.legislation.gov.uk.

- where there is a fine balance between the benefits and burdens the treatment would have on the patient and taking into account the likely risks;
- 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 patient³⁹.

119. The role of the IMCA is to represent and support the person. They will not make decisions on their behalf and such decisions will still be decided by the relevant health professional on the basis of what is in the patient's best interests. However the IMCA will speak to the person and, so far as possible, try to engage them in the decision process. The IMCA will provide information to the decision maker about the person in question and the health professional must take this information into account in deciding what is in the patient's best interests. IMCAs are entitled to information about the patient and to see his or her relevant health records. Where serious medical treatment is proposed, they will discuss with the professional the proposed course of treatment or action and any alternative treatment that may be available and may, if they consider it necessary, ask for a second medical opinion.

Referral to the Court of Protection

120. Where there are difficult or complex decisions to make on behalf of a person who lacks capacity, the matter can be referred to the Court of Protection. The Court of Protection deals, among other things, with decision-making for adults (and children in a few cases) who may lack the capacity to make decisions for themselves.

121. The courts have identified certain circumstances when referral should be made to them for a ruling on lawfulness before a procedure is undertaken. These are:

- decisions about the proposed withholding or withdrawal of artificial nutrition and hydration from patients in a permanent vegetative state or a minimally conscious state
- cases involving organ, bone marrow or peripheral blood stem cell donation by an adult who lacks the capacity to consent (see chapter 3 for information on children)

³⁹ As defined in the Independent Mental Capacity Act 2005 (Independent Mental Capacity Advocates) (Wales) Regulations 2007 (S.I. 2007/852) (W.77).

- cases involving the proposed non-therapeutic sterilisation of a person who lacks the capacity to consent to this (e.g. for contraceptive purposes), and
 - all other cases where there is a doubt or dispute about whether a particular treatment will be in a person's best interests.
122. Other cases likely to be referred to the court include those involving ethical dilemmas in untested areas (such as innovative treatments for variant CJD⁴⁰), or where there are otherwise irresolvable conflicts between healthcare staff, or between staff and family members. More information about the powers of the Court of Protection and the cases that should be referred to the court is given in the Mental Capacity Act 2005 Code of Practice.
123. The Court has held that neither abortion nor sterilisation that is incidental to the management of the detrimental effects of menstruation automatically require a referral to court if there is no doubt that this is the most appropriate therapeutic response. However, such procedures can give rise to special concern about the best interests and rights of a person who lacks capacity⁴¹. Less invasive or reversible options should always be considered before permanent sterilisation. Where there is disagreement as to the patient's best interests, a reference to court may be appropriate.
124. It should be noted that the courts may, in the future, extend the list of procedures concerning which a referral to the court is good practice.
125. A health professional who is faced with a situation that may require application to the Court of Protection should immediately contact legal advisers. Guidance on referring matters to the Court of Protection has been issued by the General Medical Council and the BMA.

Court appointed deputies

126. Whilst the decision made by the Court is always preferred, the Mental Capacity Act now provides that the Court can appoint deputies to make decisions on its behalf. This may be necessary if there are a number of difficult decisions to be made in relation to the patient. Deputies will normally be family, partners, friends or people who are well-known to the patient.

⁴⁰ *Simms v An NHS Trust* [2002] EWHC 2734 (Fam)

⁴¹ *D v An NHS Trust (Medical Treatment: Consent: Termination)* (Fam Div) [2004] 1 FLR 1110. The Official Solicitor can be contacted through the Urgent Court Business Officer out of hours on 020 7947 6000; for urgent cases see Practice Note (Official Solicitor; Urgent and Out of Hours Cases in the Family Division of the High Court) issued by the Official Solicitor, CAFCASS and the National Assembly for Wales July 2006, for further details see www.gov.uk/emergency-court-of-protection

127. As with attorneys appointed under a Lasting Power of Attorney for personal welfare, deputies may only make decisions where they have reasonable grounds to believe that the person they are acting for does not have capacity, and any decisions they take will be strictly limited to the terms specified by the Court and in accordance with the Act. Deputies are also subject to a number of restrictions in the exercising of their powers. For example, a deputy cannot refuse consent to the carrying out or continuation of life-sustaining treatment for the patient, nor can he or she direct a person responsible for the patient's healthcare to allow a different person to take over that responsibility. A deputy cannot restrict a named person from having access to the patient.
128. Health professionals should co-operate with deputies with the aim of doing what is best for the person. Where a deputy acting within their authority makes a decision that the person should not receive a treatment that is not life-sustaining or requires that a treatment that is not life-sustaining should be discontinued, that professional must act in accordance those instructions. However a deputy cannot require a health professional to give a particular type of treatment, as this is a matter for his or her clinical judgement. In such cases where a health professional has declined to give treatment, then it is good practice to seek a second opinion, although the deputy cannot insist that the health professional steps aside to allow another professional to take over the case. Deputies are supervised by the Office of the Public Guardian, and where a health professional suspects that a deputy is not acting in the interests of the patient, he or she should refer the matter to the Office of the Public Guardian⁴².

Research

129. Whenever research is proposed on a person who lacks capacity, careful consideration should be given to the ethical and legal requirements of such research. The Mental Capacity Act 2005 sets out the legal framework and provides for when such research can be carried out and for safeguards to protect people involved in the research who lack capacity, for example, ensuring that the wishes and feelings of the person who lacks capacity are respected. Anyone setting up or carrying out such research will need to make sure that the research complies with the provisions set out in the Act and will need to follow the guidance given in chapter 11 of the Mental Capacity Act (2005) Code of Practice.⁴³ The Act does not

⁴² Reference to contact details for the public guardian or further information can be found at www.gov.uk/government/organisations/office-of-the-public-guardian

⁴³ See note 6

include clinical trials, which are covered by the Medicines for Human Use (Clinical Trial Regulations) 2004.

130. The Act requires that a family member or unpaid carer must be consulted about any proposal. The researcher must ask the consultee

- For advice about whether the person who lacks capacity should take part in the project, and
- What they think the person's feelings and wishes would be, if they had capacity to decide whether to take part

131. If the consultee does not think that the person would have wanted to take part, then they cannot be included in the research.

132. If such a person cannot be identified, then the researcher must nominate a person who is independent of the research project to provide advice on the participation of the person who lacks capacity in the research. The person consulted should be asked for advice about whether the person who lacks capacity should participate in the research project and what, in their opinion, the person's wishes and feelings about taking part would be likely to be if they had capacity. The person's past or present wishes, feelings and values are most important in deciding whether they should take part in research or not. If the person without capacity shows any sign that they are not happy to be involved in the research, then they cannot be included. If the consultee does not think that the person would have wanted to take part, then they cannot be included in the research.

133. Healthcare professionals may be providing care or treatment for a person who is taking part in a research project, and may be asked for their views about what the person's feelings are or may need to advise the researchers if the person seems upset about any aspect of the research.

Withdrawing and withholding life-prolonging treatment

134. The Mental Capacity Act applies equally to withdrawing and withholding life-prolonging treatment as it applies to any other medical intervention in respect of an adult patient who lacks capacity. However, the gravity and sensitivity of these decisions are such that the assessments of capacity and of best interests are particularly important. A decision to give or withdraw treatment is ultimately a decision for the health professional and he or she must decide what is in the person's best interests. However, in reaching that decision, if it is practical and appropriate to do so, he or she must consult the person's relatives, partner, friends, carers and other professionals involved in the patient's care or treatment. It may not always be possible to consult all of these people, particularly if an urgent decision

needs to be made – for example a decision about whether it is appropriate to attempt resuscitation after severe trauma⁴⁴.

135. Legally, the use of artificial nutrition and hydration (ANH) constitutes medical treatment. Thus the legal principles which apply to the use of ANH are the same as those which apply to all other medical treatments such as medication or ventilation. The British Medical Association has suggested: that extra safeguards should be followed before a decision to withhold or withdraw ANH is made; that a senior clinician not otherwise involved in the patient's care should formally review the case; that details of cases where ANH has been withdrawn should later be made available for clinical audit. Where the patient is in a permanent vegetative state or in a minimally conscious state, legal advice must be sought regarding applying to the Court of Protection.

136. Clinicians should be aware of the Court of Appeal's decision in the case of *Burke v GMC*. This case concerned Mr Burke who had a degenerative brain disease that would eventually leave him unable to communicate his views and decisions about his treatment. Mr Burke wished to challenge General Medical Council's guidance on "Withdrawing and Withholding Life – Prolonging Treatment" and to seek a declaration concerning his right to receive artificial nutrition and hydration (ANH). The Court of Appeal ruled that:

"Autonomy and the right of self-determination do not entitle the patient to insist on receiving a particular medical treatment regardless of the nature of the treatment. Insofar as a doctor has a legal obligation to provide treatment this cannot be founded simply upon the fact that the patient demands it."

137. This case confirms that it is for the clinician to decide what treatment options are clinically indicated, and he or she will discuss with the patient the benefits and risks of each treatment. It is for the patient to decide whether he or she wishes to accept any of those treatments and a competent patient has an absolute right to refuse any treatment. However, if a patient refuses all treatment options offered to him or her and decides he or she wants an alternative form of treatment but the clinician considers that the treatment is not clinically indicated, then the clinician has no duty to provide that treatment. The clinician must however offer the patient a second opinion.

138. Where the patient has made an advance decision to refuse life-sustaining treatment, then in addition to the usual requirements for a valid

⁴⁴ Further guidance is available and a joint statement on "Decisions relating to cardiopulmonary resuscitation (October 2014)" made by the BMA, Resuscitation Council (UK) and the Royal College of Nursing.

and applicable decision it must also be in writing and signed by the patient and witnessed. It must also specifically be expressed in writing that the patient does not wish to be given that treatment even if their life is at risk (see also Chapter 3).

139. There is an important distinction between withdrawing or withholding treatment which is of no clinical benefit to the patient or is not in the patient's best interests, and taking a deliberate action to end the patient's life. A deliberate action which is intended to cause death is unlawful. Equally, there is no lawful justification for continuing treatment which is not in a patient's best interests.

Brain stem death

140. "Best interests" is a concept which only applies to the living. The courts of England and Wales have recognised what were originally referred to as the "brain death criteria" as part of the law for the purposes of diagnosing death. The criteria are more accurately described as "brain stem death criteria". Guidance on the diagnosis of brain stem death is available⁴⁵.
141. When the diagnosis of brain stem death has been confirmed, all clinical interventions can be withdrawn. If, subject to the requirements of the Human Transplantation (Wales) Act 2013, the deceased person will become an organ donor, medical interventions to facilitate donation, such as maintaining electrolyte balance, may be continued.
142. If a patient is expected to die shortly but brain stem death has not been established, the Department of Health has issued national guidance based on legal advice on the levels of pre-mortem intervention which would be acceptable, taking into account the deceased's stance on organ donation and what would be in their best interests.⁴⁶

⁴⁵ CMO Wales (98)09: A code of practice for the diagnosis of brain stem death. www.bts.org.uk

⁴⁶ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/138313/dh_109864.pdf

Chapter 5: Children and Young People

143. This chapter sets out the legal position concerning consent to and refusal of treatment by those under the age of 18. As in the case for adults, valid consent will normally be required before any treatment can lawfully be given to a child. Consent may be given by a competent child, by any person who has parental responsibility for the child or by the court. A 'child' is defined in the Children Act 1989 as any person who is under the age of 18 although children who are 16 or 17 are often referred to as 'young persons' or 'young people'. The legal position for young people of 16 or 17 is different to that of other children.
144. The Welsh Government is committed to Article 16 of the United Nations Convention on the Rights of the Child 1989, which states that no child shall be subjected to arbitrary or unlawful interference with his or her privacy.
145. If a child is not competent to give consent to treatment, then the clinician may share the information with a person who has parental responsibility if it is in the interests of the child to do so. However the privacy of the child must still be respected.

Young people aged 16 or 17

146. Section 8 of the *Family Law Reform Act 1969* provides that people aged 16 or 17 may give consent to any surgical, medical or dental treatment. 'Treatment' for the purposes of section 8 will include any procedure undertaken for the purposes of diagnosis or which is ancillary to the treatment such as an anaesthetic. As in the case for adults, consent will be valid only if it is given voluntarily by an appropriately informed patient who has capacity to consent to the particular treatment. However, unlike adults, the refusal of a competent person aged 16–17 may in certain circumstances be overridden by either a person with parental responsibility or a court (see below).
147. Section 8 of the *Family Law Reform Act 1969* applies only to the young person's own treatment. It does not apply to an intervention that is not potentially of direct health benefit to the young person, such as blood donation or non-therapeutic research on the causes of a disorder. However, a young person may be able to consent to such an intervention under the standard of Gillick competence, considered below.
148. In order to establish whether a young person aged 16 or 17 has the requisite capacity, where there is doubt, to consent to the proposed intervention, the same criteria as for adults should be used (see Chapter 1). If a young person lacks capacity to consent because of an impairment of, or a disturbance in the functioning of, the mind or brain then the Mental Capacity Act 2005 will

apply in the same way as it does to those who are 18 and over (see Chapter 2). If however they are unable to make the decision for some other reason, for example because they are overwhelmed by the implications of the decision, then the Act will not apply to them and the legality of any treatment should be assessed under common law principles. It may be unclear whether a young person lacks capacity within the meaning of the Act. In those circumstances, it would be prudent to seek a second opinion and if that does not resolve the issue, seek legal advice. More information on how the Act applies to young people is given in chapter 12 of the Mental Capacity Act 2005 Code of Practice.

149. If there is no reason to doubt the 16 or 17-year-old's capacity to give valid consent then it is not legally necessary to obtain consent from a person with parental responsibility for the young person in addition to the consent of the young person. It is, however, good practice to involve the young person's family in the decision-making process – unless the young person specifically wishes to exclude them – so long as the young person consents to their information being shared.

Competent Children under 16

150. The case of *Gillick*⁴⁷ determined that children who have sufficient understanding and intelligence to enable them to understand fully what is involved in a proposed intervention, will have the capacity to give their consent to that intervention. This is sometimes described as being 'Gillick competent'. A child under 16 years of age may be Gillick competent to consent to medical treatment, research, donation or any other activity that requires their consent.
151. The concept of *Gillick* competence is said to reflect the child's increasing development to maturity. The understanding required for different interventions may vary considerably. A child may have the capacity to consent to some interventions but not to others. The child's capacity should be carefully assessed in relation to each decision.
152. In some cases, for example because of a mental disorder, a child's mental state may fluctuate significantly so that on some occasions the child appears *Gillick* competent in respect of a particular decision and on other occasions does not. In cases such as these, careful consideration should be given to whether the child is truly *Gillick* competent at any time to take this decision.
153. If the child is *Gillick* competent and is able to give voluntary consent after receiving appropriate information, that consent will be valid and additional consent by a person with parental responsibility will not be required.

⁴⁷ *Gillick v West Norfolk and Wisbech AHA* [1986] AC 112.

However where the decision will have on-going implications, such as long-term use of contraception, it is good practice to encourage the child to inform his or her parents unless it would clearly not be in the child's best interests to do so. If a child cannot be persuaded to inform his or her parents, or it is not in the child's interest to inform them, then every effort must be made to help the child find another adult (such as another family member or a specialist youth worker) to provide support⁴⁸.

The requirement of voluntariness

154. Although a child or young person may be competent to give consent, valid consent must be given voluntarily. This requirement must be considered carefully. Children and young people may be subject to undue influence by their parents, other carers, or a potential sexual partner, and it is important to establish that the decision is that of the individual him or herself.

Child or young person with capacity refusing treatment

155. Where either a young person of 16 or 17 with capacity or a Gillick competent child under 16, refuses treatment, it is possible that such a refusal could be overruled if it would in all probability lead to the death of the child or young person or result in severe permanent injury.
156. In the case of *Re W (a minor) (medical treatment)*⁴⁹ the court stated that it has jurisdiction to override a refusal of a child/young person, at least where they seek to refuse treatment in circumstances that will, in all probability, lead to the death of the child/young person or to severe permanent injury; or where there is a serious and imminent risk that the child/young person will suffer grave and irreversible mental or physical harm.
157. The courts have, in the past, also found that parents can consent to their competent child being treated even where the child/young person is refusing treatment.⁵⁰ However this case pre-dates the Human Rights Act 1998 and the Mental Capacity Act and it would therefore be prudent to seek legal advice if faced with a competent child or young person who is refusing to consent to treatment, to determine whether it is lawful to treat the child.
158. Where the treatment involved is for mental disorder, consideration should be given to using mental health legislation.
159. The changes made to section 131 of the Mental Health Act 1983 by section 43 of the Mental Health Act 2007 mean that when a young person of 16 or 17 has capacity (as defined in the Mental Capacity Act 2005) and does not

⁴⁸ *Axon v Secretary of State for Health* [2006] EWHC 37 (Admin)

⁴⁹ *Re W (a minor) (medical treatment)* [1992] 4 All ER 672

⁵⁰ *Re R (a minor) (wardship: medical treatment)* [1991] 4 All ER 177

consent to admission for treatment for mental disorder (either because they are overwhelmed, do not want to consent or refuse to consent), they cannot then be admitted informally on the basis of the consent of a person with parental responsibility (see chapter 19 of the Code of Practice to the Mental Health Act 1983⁵¹).

160. A life threatening emergency may arise in connection with a child when consultation with either a person with parental responsibility or the court is impossible, or the persons with parental responsibility refuse consent despite such emergency treatment appearing to be in the best interests of that child.
161. In such cases the courts have stated that doubt should be resolved in favour of the preservation of life and it will be acceptable to undertake treatment to preserve life or prevent serious damage to health.

Children without capacity

162. Where a child who is under the age of 16 is not competent to give consent, consent can be given on their behalf by any one person with parental responsibility (if the matter is in the 'zone of parental control'⁵²) or by the Court. As is the case where patients are giving consent for themselves, those giving consent on behalf of child patients must have the capacity to consent to the intervention in question, be acting voluntarily, and be appropriately informed. The power to consent must be exercised according to the "welfare principle": that the child's "welfare" or "best interests" must be paramount.
163. Where a young person of 16 or 17 lacks capacity then they are treated the same as an adult who lacks capacity and any decision must be taken in accordance with the Mental Capacity Act. The Act requires that in making decisions any person who has an interest in the welfare of that person must be consulted about their best interests and their views taken into account. In the case of a young person this is likely to include the parents or any other person with parental responsibility.
164. Even where a child does not have competency to consent on their own behalf, if possible it is good practice to involve the child as much as possible in the decision-making process. If a child has been competent but then loses competence, then any views he or she may have had while they had competence should be taken into account in making any decision about treatment.

⁵¹https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/435512/MHA_Code_of_Practice.PDF

⁵² The concept of the 'zone of parental control' derives largely from case law from the European Court of Human Rights in Strasbourg. Chapter 36 of the Code of Practice to the Mental Health Act 1983, as amended, gives guidelines about what may fall in the zone, which will depend on the particular facts of the case.

165. Where necessary the courts can, as with competent children, over-rule a refusal by a person with parental responsibility. In some circumstances it may be appropriate to refer important decisions to the Court, even if those with parental responsibility consent to a particular intervention.

Parental Consent

166. The *Children Act 1989* defines “parental responsibility” as “all the rights, duties, powers, responsibilities and authority which by law a parent has in relation to the child and his property.” This includes the right to consent or refuse to medical treatment on behalf of the child but this is not an absolute right and any power must be exercised for the benefit of and protection of the child. A person with parental responsibility must always act in the best interests and welfare of the child. In some cases even where parental consent has been given the decision may still need to be sanctioned by the Court.

167. The *Children Act 1989* sets out persons who may have parental responsibility. These include:

- the child’s mother
- the child’s father if he was married to the mother at the time of birth
- a second female parent of a child conceived via artificial insemination⁵³ if she was married to or was the civil partner of the mother at the time of birth
- unmarried fathers who can acquire parental responsibility in several different ways:
- for a child born before 1 December 2003 unmarried fathers have parental responsibility if they:
 - marry the mother of their child or has a parental responsibility order from the court
 - register a parental responsibility agreement with the court or by an application to court
- for a child born after 1 December 2003, unmarried fathers have parental responsibility if they
 - register the child’s birth jointly with the mother at the time of birth⁵⁴

⁵³ For the purposes of section 43 of the Human Fertilisation and Embryology Act 2008

- reregister the birth if they are the natural father
- marry the mother of their child
- enter into a parental responsibility agreement with the mother of the child and register the agreement with the Family Court
- obtain a parental responsibility order from the court
- become named in a child arrangements order which provides that the child will live with them
- a second female parent of a child conceived via artificial insemination who was not married to or the civil partner of the mother if they:
 - register the child's birth jointly with the mother at the time of birth⁵⁵
 - reregister the birth
 - marry or enter into a civil partnership with the mother of their child
 - enter into a parental responsibility agreement with the mother of the child and register the agreement with the Family Court
 - obtain a parental responsibility order from the court
 - become named in a child arrangements order which provides that the child will live with them
- A step parent who is married to or a civil partner of a parent of the child if:
 - They enter into a parental responsibility agreement with those birth parents who hold parental responsibility and register the agreement with the Family Court
 - obtain a parental responsibility order from the court
- the child's legally appointed guardian⁵⁶
- a person in whose favour the court has made a child arrangements order which provides that the child shall live with that person

⁵⁴ Under section 4 of the Children Act 1989, unmarried fathers who register their child's birth jointly with the mother will automatically acquire parental responsibility.

⁵⁵ Under section 4 of the Children Act 1989, unmarried fathers who register their child's birth jointly with the mother will automatically acquire parental responsibility.

⁵⁶ Under section 5 of the Children Act 1989 courts may appoint a guardian for a child who has no parent with parental responsibility. Parents with parental responsibility may also appoint a guardian in the event of their own death.

- a local authority designated in a care order or interim care order in respect of the child
- a local authority or other authorised person who holds an emergency protection order in respect of the child.

168. In some cases a person may not have parental responsibility for the child but may, for the time being, be responsible for their care. For example a person might be a child minder or the member of staff of a boarding school having regular care of the child. That person may consent to medical treatment on behalf of the child if it is reasonable to act without first obtaining the consent of the person with parental responsibility, for example, where the treatment is urgently required or is trivial. In the event of doubt specific enquiry should be made.

169. Consent given by one person with parental responsibility is valid, even if another person with parental responsibility withholds consent. However, the courts have stated that a “small group of important decisions” should not be taken by one person with parental responsibility against the wishes of another, citing in particular non-therapeutic male circumcision⁵⁷ and immunisation⁵⁸.

170. Where persons with parental responsibility disagree as to whether non-therapeutic procedures are in the child’s best interests, legal advice should be sought. It is possible that major experimental treatment, where opinion is divided as to the benefits it may bring the child, might also fall into this category of important decisions and, again, legal advice should be sought in such circumstances. A health professional should not rely on the consent of a parent if he or she has any doubts about whether the parent is acting in the interests of child. The Welsh Government guidance in *Safeguarding Children: Working Together Under the Children Act 2004*⁵⁹ covers situations where abuse or neglect is suspected.

171. In order to consent on behalf of a child, the person with parental responsibility must have capacity. Where the parent of a child is under 16, he or she will only be able to give valid consent for the child’s treatment if they would have been Gillick competent to consent if they themselves were being given the treatment.

⁵⁷ Re J (A Minor) (Prohibited Steps Order: Circumcision) [2000] 1 FLR 571 at 577. Female circumcision is always prohibited under the Female Circumcision Act 1985.

⁵⁸ Re C (Welfare of Child: Immunisation) [2003] EWCA Civ 1148. Guidance on the immunisation and vaccination of children is in chapter 2 of the ‘*Green Book*’ published by the Department of Health.

⁵⁹ Safeguarding Children: Working Together Under the Children Act 2004, www.gov.wales/topics/health/publications/socialcare/circular/nafwc1207/?lang=en

172. Where a child is a ward of court, no important step may be taken in the life of the ward without the prior consent of the court. This is likely to include more significant medical interventions but not treatment for minor injuries or common diseases of childhood.

173. In an emergency, it is justifiable to treat a child who lacks capacity without the consent of a person with parental responsibility, if it is impossible to obtain consent in time and if the treatment is vital to the survival or health of the child.

Person with parental responsibility refusing consent

174. As in the case for adults the decision to give medical treatment to a child without capacity is ultimately a decision for the health professional based upon their clinical judgement. However in such circumstances the Court has held that the views of the parents should be “accorded profound respect and given weight although their views cannot be decisive”⁶⁰.

175. The European Court of Human Rights judgment in a case where doctors treated a child contrary to his mother’s wishes, without a court order (*Glass v United Kingdom*⁶¹), made clear that the failure to refer such cases to the court is not only a breach of professional guidance but also potentially a breach of the European Convention on Human Rights. In situations where there is continuing disagreement or conflict between those with parental responsibility and doctors, and where the child is not competent to provide consent, the court should be involved to clarify whether a proposed treatment, or withholding of treatment, is in the child’s best interests. Parental refusal can only be overridden in an emergency. All NHS bodies should have procedures for dealing with such circumstances.

Research

176. Where children lack capacity to consent for themselves, parents may give consent for their child to be entered into a trial where the evidence is that the trial therapy may be at least as beneficial to the patient as the standard therapy. It may also be compatible with the welfare principle for a person with parental responsibility to give consent to a research intervention that is not strictly in the best interests of the child, but is not against the interests of the child either. Such an intervention must involve only minimal burden to the child.

177. Decisions about experimental treatment must be made in the child’s best interests.

Vaccination and Immunisation

⁶⁰ Re Wyatt (A Child) (Medical Treatment: Continuation of Order) [2005] 2 FLR 480.

⁶¹ See note 2

178. Advice on gaining consent for the immunisation and vaccination of children is given in the '*Green Book*' published by the Department of Health.⁶² Where a child or person with parental responsibility is refusing consent to be immunised then the same principles as set out above will apply. In such cases the health professional should seek further advice.

Children lacking capacity and bone marrow donation

179. This is covered by the Human Tissue Authority's code of practice on donation of allogeneic bone marrow and peripheral blood stem cells for transplantation, and healthcare professionals should consult this for detailed information on the legal requirements and how to proceed.⁶³

⁶² www.gov.uk/government/collections/immunisation-against-infectious-disease-the-green-book

⁶³ See Code of practice 6 - Donation of allogeneic bone marrow and peripheral blood stem cells, www.hta.gov.uk/guidance-professionals/codes-practice/code-practice-6-donation-allogeneic-bone-marrow-and-peripheral-blood-stem-cells