



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Reference Guide for Consent to Examination or Treatment

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Introduction

This booklet provides guidance on the law as it applies to Wales concerning consent to physical interventions on patients. It applies to any health professional whether they are employed by an NHS body and working in a hospital or providing treatment in the community or Primary Care Setting. The booklet sets out the legal requirements for obtaining valid consent and gives guidance on the circumstances in which treatment may be given to a patient who cannot give his or her valid consent. It should be noted that this guidance is specific to consent for physical interventions on living patients, and the following areas are therefore not included:

- participation in observational studies
- the use of personal information
- the use of organs or tissue after death

NHS bodies, GP surgeries and other persons providing public health services in Wales should review their consent policies and amend where necessary to reflect the guidance contained within this document.

Standard 8c of *Healthcare Standards for Wales* requires healthcare organisations to ensure that informed consent is obtained appropriately for all contacts with patients and service users. Healthcare Inspectorate Wales will be assessing compliance with this standard as part of its annual reviews of healthcare organisations.

The guidance reflects the Welsh Assembly Government commitment to promoting equality of opportunity for all, whatever their race, language, religion or other belief system, disability, age gender and sexual orientation, to ensure that every citizen has the opportunity to make informed choices regarding their health care in Wales, and that compliance to equality legislation is met. The Government of Wales Act 2006, Section 77 places a unique statutory duty ensuring that equality of opportunity is embedded within its work.

The Welsh Assembly Government re-established the Consent Advisory Group consisting of representatives from NHS bodies and professional bodies to advise on this guidance. A consultation report is available at <http://www.wales.nhs.uk/sites3/page.cfm?orgid=465&pid=11930>

1. Principles of Consent

1. It is a general legal and ethical principle that valid consent must be obtained before starting treatment, physical investigation or providing personal care for a patient. This principle reflects the right of patients to determine what happens to their own bodies and is a fundamental part of good practice. A health professional 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

- 1.1 Case law (“common law”) has established that touching a patient without valid consent may constitute the civil or criminal offence of battery. Furthermore, if health professionals fail to obtain proper and informed consent and the patient 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 from patients through the NHS complaints procedure or to professional bodies.
- 1.2 The guidance covers case law on consent which has evolved significantly over the last decade. Of particular relevance are the following cases that health professionals should be aware of:
 - *Glass v United Kingdom*¹;
 - *Chester v Afshar*²;
 - *R (on the application of Burke) v General Medical Council*³.
- 1.3 Health professionals must also remember their duty to keep themselves informed of legal developments subsequent to this guidance and which may have a bearing on their practice. 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 health professionals involved in examining or treating patients.

Relevant legislation

- 1.4 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. Courts now take into account the case law of the European Court of Human Rights in Strasbourg, as well as the case law of England and Wales. The guidance in this booklet is compatible with the existing case-law of the European Court of Human

¹ (Application No 61827/00) [2004] ECHR 102. See paragraph 5.28

² [2004] All ER 587. See paragraph 2.25.

³ [2005] EWCA Civ 1003. See paragraph 4.40.

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).

- 1.5 The *Human Tissue Act 2004* now provides a legal framework for the removal of organs or tissue from patients. Insofar as it relates to living patients, it provides that consent must be obtained where any tissue or organs of that patient are stored and used for certain specified purposes, other than for the diagnosis or treatment of that patient.
- 1.6 From 1 October 2007, the *Mental Capacity Act 2005* applies in relation to the care or treatment of patients who lack capacity to consent to treatment. Most of the provisions in the Act apply to patients of 16 years or over. The Act now provides a statutory basis for a health professional to treat such a patient without consent but subject to safeguards that are contained in the Act. It mainly reflects existing common law principles contained in case law. The *Mental Capacity Act* is supported by a Code of Practice which assists health professionals to apply the principles in the Act.
- 1.7 The *Mental Health Act 2007* will amend the *Mental Capacity Act* to introduce safeguards for compliant patients who lack capacity and are detained in circumstances amounting to a deprivation of liberty⁴.
- 1.8 The standards expected of health 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 will also indicate where regulatory bodies have set out more stringent requirements. 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.
- 1.9 The purpose of this guidance is to explain the law on consent and 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.

⁴ These safeguards are due to come into force in April 2009.

2. Seeking Consent

Valid consent

2.1 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 patient, someone with parental responsibility⁵ or a person who has authority under a Power of Attorney. Consent will not be legally valid if the patient 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 patient does not have capacity to give consent, then treatment may be given providing it is given in accordance with the Mental Capacity Act 2005.

Does the patient have capacity?

2.2 The Mental Capacity Act 2005 now applies in relation to determining whether a patient 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 not⁶. A person lacks capacity if he or she is unable to make a decision for themselves in relation to a matter because they have an impairment of, or disturbance of the mind or brain. This impairment or disturbance can either be temporary or permanent. In ascertaining a patient’s capacity, the health professional must not make a judgement on the basis of the patient’s appearance or on any other aspects of his or her behaviour. Where there is any doubt about a person’s capacity, a formal assessment must be arranged. If a formal assessment is inconclusive an application for determination of person’s capacity may be made to the Court of Protection.

2.3 The Mental Capacity Act provides that a person is unable to make a decision if they are unable:

- to understand the information relevant to the decision;
- to retain that information;
- to use or weigh that information as part of the process of making the decision; or
- to communicate his or her decision, whether by talking, using sign language or any other means.

2.4 If a person fails to meet one or more of the above criteria they will not have capacity to make a decision. If a person is assessed as not having capacity to make a particular decision it should not be assumed that they do not have capacity to make any decisions.

⁵ See chapter 5

⁶ All the principles of the Act are set out in Chapter 4, paragraph 4.1.

- 2.5 The British Medical Association has published advice on the assessment of capacity⁷.
- 2.6 A patient'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. If however the patient is suffering from a temporary incapacity, then the way in which he or she may be treated is discussed further in paragraph 4.10 of Chapter 4.
- 2.7 Capacity should not be confused with a health professional's assessment of the reasonableness of the patient's decision. The patient is entitled to make a decision which is based on their own religious belief or value system. Even if it is perceived by others that the decision is unwise or irrational, the patient may still make that decision if he or she has capacity to do so.
- 2.8 An irrational decision has been defined as one which is so outrageous in its defiance of logic or of accepted moral standards, that no sensible person who had applied his or her mind to the question could have arrived at it⁸. This does not necessarily mean that the person lacks capacity. However if the decision is based upon the patient's misperception of reality stemming from a disturbance or impairment of the mind or brain, then he or she may not have capacity to make that decision. For example, if a patient who is schizophrenic refuses treatment because he wrongly believes that the doctor is trying to murder him, or a patient with anorexia nervosa refuses food because she is unable to comprehend her failing physical condition - then these would be relevant factors in assessing whether the patient has capacity.
- 2.9 Some cases may not be that clear, and the patient who would normally have capacity may refuse treatment because of a phobia. The courts have held that a woman who required a caesarean to save her and her baby's life and refused anaesthetic because of a phobia of needles was suffering from a temporary lack of capacity brought about by panic and fear⁹.
- 2.10 The patient 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 patient does not believe that advice. The patient may be refusing treatment because they have a poor relationship with the health professional and simply do not trust them, or the patient may consider that the professional is not sufficiently senior to give the advice.

⁷ BMA and The Law Society, Assessment of mental capacity: guidance for doctors and lawyers, 2004

⁸ Re MB (Medical Treatment)(1997) 38 BMLR 175 (CA)

⁹ See MB (Medical Treatment) as above

- 2.11 Care should be taken not to underestimate the capacity of a patient with a learning disability. Many people with learning disabilities have the capacity to consent if time is spent explaining to the individual the issues in simple language, using visual aids and signing if necessary.
- 2.12 Further information about assessing the capacity of patients generally can be found in the Mental Capacity Act 2005 Code of Practice¹⁰.

Patient Communication

- 2.13 A patient 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 patient to communicate, whatever their condition. In some cases it may be because English is not the patient's first language. Health professionals should take all steps which are reasonable in the circumstances to facilitate communication with the patient, using interpreters or communication aids as appropriate and ensuring that the patient feels at ease. In particular careful consideration should be given to the way in which information is explained or presented to the patient.
- 2.14 Where possible, health professionals are encouraged to discuss conditions and treatment options in the Welsh medium or other language when this is the patient's first language. However, the health professional must feel sufficiently confident in his or her ability to speak the language when seeking the patient's consent to examination or treatment so as to avoid misunderstandings. If the health professional does not feel sufficiently confident, but the patient can speak and understand English to a level where they sufficiently understand and can give consent, then English should be used when obtaining consent. Otherwise, reasonable steps to facilitate communication with the patient, using interpreters or communication aids as appropriate, should be used.
- 2.15 Where appropriate, those who know the patient well, including their family, carers and staff from professional or voluntary support services, may be able to advise on the best ways to communicate with the person.
- 2.16 Where sign language is considered to be the most appropriate method of communication, arrangements should be made for a qualified British Sign Language (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 often complicated procedures. By using the services of a qualified BSL interpreter, health professionals may be more confident that the patient has fully understood the procedures and potential risks involved when giving their consent. It also ensures that the patient's wishes are properly communicated and removes the risk of undue influence by family or friends (See paragraph 2.16 below).

¹⁰ The Code of Practice is available on the Ministry of Justice website. See www.moj.gov.uk.

Is the consent given voluntarily?

- 2.17 To be valid, consent must be given voluntarily and freely, without pressure or undue influence being exerted on the patient either to accept or refuse treatment. 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 patient on their own to establish that the decision is truly that of the patient.
- 2.18 When patients are seen and treated in environments where involuntary detention may be an issue, such as prisons and mental hospitals, there is a potential for treatment offers to be perceived coercively, whether or not this is the case. Coercion invalidates consent and care must be taken to ensure that the patient makes a decision freely. Coercion should be distinguished from providing the patient with appropriate reassurance concerning their treatment, or pointing out the potential benefits of treatment for the patient's health. However, threats such as withdrawal of any privileges or loss of remission of sentence for refusing consent, or using such matters to induce the patient to give consent, are not acceptable. Consent that has been obtained by fraud will not be valid¹¹

Has the patient received sufficient information?

- 2.19 To give valid consent the patient needs to understand in broad terms the nature and purpose of the procedure. Any misrepresentation of these elements will invalidate consent. Where relevant, information about anaesthesia should be given as well as information about the procedure itself.
- 2.20 The use of patient information leaflets is considered to be an effective tool that can be used by health professionals to provide patients with the information they need to help them to arrive at an informed decision. Patients can review the information after the consultation, which may prompt the patient to ask further questions of the health professional to more fully understand the treatment being proposed. In this context, the use of patient information leaflets is considered by the Welsh Assembly Government to be an example of best practice. The use of Easyread in the leaflets which are specially written to assist people with learning disabilities is also encouraged.
- 2.21 However, health professionals must not regard the use of patient information leaflets as providing the patient 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

¹¹ Appleton v Garrett [1997] 8 Med LR 75.

patient, and merely providing a patient with an information leaflet will not meet the practitioner's obligations. In some cases a patient's consent may be obtained by post and this gives the patient time to read and reflect on the consent form and information provided. However, any person carrying out a procedure on a patient must ensure that, immediately before the procedure, the patient has understood the information and that they still give their consent. If the patient has queries or concerns he or she must be given time to consider any additional information.

- 2.22 Although informing patients of the nature and purpose of procedures may be sufficient for the purposes of giving valid consent as far as any claim of battery is concerned, this is **not** sufficient to fulfil the legal duty of care to the patient. Failure to provide other relevant information may render the professional liable to an action for negligence if a patient subsequently suffers harm as a result of the treatment received.
- 2.23 The requirements of the legal duty to inform patients have been significantly developed in case law. In 1985, the House of Lords decided in the *Sidaway*¹² case that the legal standard to be used when deciding whether adequate information had been given to a patient should be the same as that used when judging whether a doctor had been negligent in their treatment or care of a patient: a doctor would not be considered negligent if their practice conformed to that of a responsible body of medical opinion held by practitioners skilled in the field in question (known as the "Bolam test").¹³ Whether the duty of care had been satisfied was therefore primarily a matter of medical opinion. However, *Sidaway* also stated that it was open to the courts to decide that information about a particular risk was so obviously necessary that it would be negligent not to provide it, even if a "responsible body" of medical opinion would not have done so.
- 2.24 Since *Sidaway*, judgements in a number of negligence cases (relating both to the provision of information and to the standard of treatment given) have shown that courts are willing to be critical of a "responsible body" of medical opinion. It is now clear that the courts will be the final arbiter of what constitutes responsible practice, although the standards set by the health professions for their members will still be influential.
- 2.25 A recent decision by the House of Lords, *Chester-v-Afshar*¹⁴, has established that a health professional can now be liable even in cases where it cannot be proved on the balance of probabilities that their negligence caused harm to the patient. In this case Miss Chester could not prove that she would never have consented to the operation if she had been informed of the risks, but the surgeon was still liable because Miss Chester had not given her informed consent.

¹² *Sidaway v Board of Governors of the Bethlem Royal Hospital* [1985] AC 871

¹³ *Bolam v Friern Hospital Management Committee* [1957] 2 All ER 118

¹⁴ *Chester v Afshar* [2004] All E.R. 587.

2.26 This decision has serious implications for health professionals. Failure to take adequate consent now over-rides any argument that such failure did not cause the adverse outcome, provided that the warning ought to have been given, and the condition or consequence which ought to have been mentioned actually develops.

2.27 The General Medical Council gives guidance on the type of information that patients may need to know before making a decision and has stated that doctors should do their best to find out about patients' *individual* needs and priorities when providing information about treatment options. The guidance also emphasises that if the patient asks specific questions about the procedure and associated risks these should be answered truthfully.¹⁵

2.28 When giving patients advice about 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 and material risks;
- ensure that warnings are properly recorded in the notes;
- invite the patient to sign the relevant entry to confirm that he/she has been given the warning, has understood it, and accepts the risk;
- make a full entry in the notes, preferably signed by the patient, if treatment is refused, including the reason when given.

Withholding information

2.29 Some patients 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. 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 patient 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 patients' 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 answer¹⁶.

¹⁵ GMC, Seeking patients' consent: the ethical considerations, November 1998

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

Additional procedures

- 2.30 During a procedure where the patient is under anaesthetic, it may become evident that the patient could benefit from an additional procedure. 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 patient's views and that the patient 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 patient expresses that they do not want a particular procedure to be carried out (for example, that a mastectomy should not be carried out after a frozen section biopsy result) then their wishes must be respected. However, if it is apparent that a procedure that has not been anticipated is necessary, and was not within the scope of the consent given by the patient but it would be unreasonable to delay the procedure until the patient regains consciousness (particularly if the procedure is to save the patient's life or prevent serious harm), it may be justified to perform the procedure on the grounds that it is in the patient's best interests.
- 2.31 The health professional should do no more than is reasonably required, in the best interests of the patient in accordance with the requirements of the Mental Capacity Act 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 life.¹⁷

Subsequent use of removed tissue

- 2.32 The Human Tissue Act 2004 repeals and replaces the Human Tissue Act 1961, the Anatomy Act 1984 and the Human Organ Transplants Act 1989 and regulates the removal, storage and use of human tissue. Where human tissue which is defined as material which has come from a human body and consists of, or includes, human cells (but does not include cell lines or hair and nails from living people) is removed, the Act provides that certain specified activities (including research) as set out in Schedule 1 require the consent of the patient. Consent must be given by an appropriate person and penalties of up to three years imprisonment or a fine, or both, can be imposed for failure to obtain or misuse of consent. Live gametes and embryos are excluded as they are regulated under the Human Fertilisation and Embryology Act 1990 (See paragraphs 2.46 – 2.48).

¹⁷ Re F(Mental Patient: Sterilisation) [1990] 2 AC 1; [1989] 2 All ER at 37 per Butler-Sloss LJ

2.33 Full details about these activities and when consent is required can be found in Codes of Practice published by the Human Tissue Authority¹⁸.

Attendance by students and trainees

2.34 Where a student or trainee health professional is undertaking examination or treatment of the patient where the procedure will further the patient'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 professional is a student, although it would always be good practice to do so and consent in the usual way will still be required.

2.35 In contrast, where a student proposes to conduct a physical examination which is not part of the patient'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.

2.36 A patient'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. Patients 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

2.37 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. As a matter of good practice, the same principles should be applied to clinical photography.

2.38 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 patient has been given sufficient information for valid consent, making it clear that the recording could be used during legal proceedings, as part of a

¹⁸ The Human Tissue Authority's Codes of Practice can be found on www.hta.gov.uk.

medical record, or possibly as a tool for teaching, audit or research. The need to obtain consent applies equally if the patient has requested the recording, photograph or radiograph.

- 2.39 The GMC guidance¹⁹ gives detailed advice in the use of recordings when treating or assessing patients. Further information can also be found in the Information Commissioners “Use and Disclosure of Health Data: Guidance on the Application of the Data Protection Act 1998” May 2002.

Who should seek consent?

- 2.40 The health professional giving the treatment or carrying out the intervention is responsible for ensuring that the patient 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, 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 should consent be sought?

- 2.41 The seeking and giving of consent is usually a process, rather than a one-off event. It is good practice where possible for both major or minor interventions to seek the patient’s consent to the proposed procedure well in advance, when there is time to respond to the patient’s questions and provide adequate information (see above paragraphs 2.19 – 2.31). Clinicians, or if the procedure is carried out in a Primary Care Setting, the GP should then check, before the procedure starts, that the patient 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

- 2.42 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

¹⁹ GMC Making and Using Visual and Audio Records of Patients 2002.

has 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.

- 2.43 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 patient's capacity, it is important, *before* the patient is 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.
- 2.44 Whilst obtaining the patient'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. 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 always be obtained.
- 2.45 If the patient has capacity, but is illiterate, the patient 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 patient has chosen to make their mark in this way to be recorded in the case notes. Similarly, if the patient has capacity, and wishes to give consent, but is physically unable to mark the form, this fact should be recorded in the notes. If consent has been validly given, the lack of a completed form is no bar to treatment.

Requirements concerning gametes

- 2.46 It is a legal requirement under the *Human Fertilisation and Embryology Act 1990* that consent to the storage and use of gametes must be given in writing after the person has received such relevant information as is proper and had an opportunity to receive counselling. 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.
- 2.47 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.

- 2.48 The UK Government intends to include provisions in the Human Tissue and Embryos Bill to address cases where the taking of gametes is in the patient's best interests but the patient is unable to give written consent or lacks capacity to consent to the storage of the gametes. However for the present, further guidance is available from the Human Fertilisation and Embryology Authority²⁰.

Living donor transplantation

- 2.49 Any transplantation of an organ from one living person to another must be carried out in accordance with the requirements of the Human Tissues Act 2004. All such transplants require the prior approval of the Human Tissue Authority²¹.
- 2.50 Where it is proposed that a transplantation 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 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 below (see paragraph 5.33 – 5.34).

Research and innovative treatment

- 2.51 The same legal principles apply when seeking consent from patients 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, the GMC states that "particular care" should be taken to ensure that possible research subjects have the fullest possible information 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 2004²².
- 2.52 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

²⁰ See www.hfea.gov.uk. The Human Tissue Authority Codes of Practice contain further guidance.

²¹ See www.hta.gov.uk

²² S.I. 2004/1031.

patients before their consent is sought, along with information about standard alternatives. It is good practice to give patients 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.

- 2.53 Where a patient does not have capacity to consent then it will be unlawful to carry out research unless that research is in the patient's best interest in accordance with the Mental Capacity Act 2005.

Duration of consent

- 2.54 When a patient 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 GMC guidance states that a doctor or member of the healthcare team should inform the patient and reconfirm their consent. In the light of paragraphs 2.19 – 2.31 above, the health professional should consider whether the new information should be drawn to the attention of the patient and the process of seeking consent repeated on the basis of this information. 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.
- 2.55 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. The position of patients who lack capacity is covered in chapter 4.

3. Patients Refusing Treatment

Patients' right to refuse treatment

- 3.1 If an adult with capacity makes a voluntary and appropriately informed decision to refuse treatment this decision **must** be respected, (except where a statutory exception applies such as the Mental Health Act 1983 (see below)) and any attempt to treat that patient against his or her wishes could amount to 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. 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)* [1994] 1 WLR Fam 95, Lord Donaldson 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”.

- 3.2 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 4.40 on *Burke v GMC*)

Treatment given under the Mental Health Act 1983

- 3.3 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 in accordance with Parts IV or 4A of the Mental Health Act²³ to give that treatment. Treatment for a mental disorder means any treatment the purpose of which is to cure or alleviate the effects of the disorder itself²⁴. However the courts have extended the scope to include “a range of acts ancillary to the core treatment”²⁵. For example the courts have held that force-feeding a patient with anorexia

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

²⁴ This definition will be extended by the Mental Health Act 2007 when it comes into force to include treatment that will prevent a worsening of the disorder or one or more of its symptoms or manifestations.

²⁵ *B v Croydon HA* [1995] 1 All ER 683 (CA)

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"²⁶.

- 3.4 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)*²⁷ 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.
- 3.5 Further information about consent and the Mental Health Act 1983 is in the Mental Health Act Code of Practice²⁸.

Other Exceptions

- 3.6 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 consent²⁹. Although the Act has a power for regulations to be made concerning the treatment of such persons without their consent, these regulations have never been made.

²⁶ *Herczegfalvy v Austria* (1993) 15 EHRR 437 (ECtHR) applied in *R(on the application of Wilkinson) v Broadmoor Special Hospital Authority* [2002] 1 WLR 419 (CA) and *R(on the application of N) v M* [2003] 1 WLR 562 (CA).

²⁷ [1994] 1 W.L.R. 290.

²⁸ Welsh Office *Code of Practice: Mental Health Act 1983* (1999) is shortly to be replaced by the Welsh Assembly Government *Mental Health Act 1983 Code of Practice*

²⁹ The Health and Social Care Bill was introduced in Parliament in November 2007. This will amend the Public Health (Control of Disease) Act 1984 to extend the regulation making powers to take account of the World Health Organisation International Health Regulations 2005.

Medical treatment and an unborn child

- 3.7 If an adult patient 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 intervene³⁰. Medical intervention can only be taken if it is believed that the patient lacks capacity to consent (see Chapter 4)³¹. 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

- 3.8 A patient 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 and providing he or she is acting in the best interest of the patient.
- 3.9 Assessing capacity during a procedure may be difficult and, as noted above, factors such as pain, panic and shock may diminish capacity to consent. The health professional should try to establish whether at that time the patient has capacity to withdraw a previously given consent. If capacity is lacking, it may sometimes be justified to continue in the patient's best interests (see chapter 4), although this should not be used as an excuse to ignore distress.

Advance statements

- 3.10 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 and are unable to express their wishes for themselves. There are various different types of statements sometimes referred to as "living

³⁰ Re MB (Medical Treatment) [1997] 2 FLR 426, 440.

³¹ Attorney-General's Reference (No 3 of 1994) [1997] 3 WLR 421, 428-429, 440 and Re MB (Medical Treatment) [1997] 2 FLR 426, 440

wills” or “advance directives”. A patient may make an advance decision in accordance with the Mental Capacity Act to refuse a particular type of treatment, or may make a general statement about their treatment or course of action to be taken.

Advance Decisions to refuse treatment

3.11 A person who is 18 or over and has capacity may make an advance decision to refuse treatment to take effect at a time when he or she no longer has capacity. Any advance decision that complies with the Mental Capacity Act 2005 and is valid and applicable to the treatment that is proposed, has the same effect as if that person has capacity and is contemporaneously refusing consent to treatment. In other words, if a person has made a valid and applicable advance decision and has the right to refuse the treatment when he or she makes that advance decision, they will have the same right when they no longer have capacity unless a statutory exception applies. A health professional who knowingly treats a person where there is an advance decision could be acting unlawfully and liable to a claim of battery. This type of advance decision is only valid if it is to refuse treatment.

3.12 A valid and applicable advance decision:

- must clearly specify the type of treatment that is being refused although this can be expressed in layman’s terms;
- may be withdrawn or altered at any time whilst the patient has capacity;
- may be overridden by the donee of a lasting power of attorney who is appointed after the decision has been made. This only applies where authority has been conferred on that donee to give or refuse consent to the type of treatment that is specified in the decision;
- will not be valid if the person has done anything that might be perceived as acting inconsistently with that decision, or there are reasonable grounds for believing that there are circumstances that had the person known about he or she would not have made the decision. For example there may be a medical advancement of which a person was unaware of at the time he or she made the advance decision, which could significantly improve that person’s condition;
- if it relates to life-sustaining treatment, will not be applicable unless the person has made a written statement which has been signed and witnessed that the decision is to apply even if the person’s life is at risk.

3.13 A health professional will not be acting unlawfully if he or she treats a person and is genuinely unaware of the existence of an advance

decision. Conversely they will not act unlawfully if they act in accordance with an advance decision that they believe is valid and applicable at the time but is later proved to be invalid. If there is any doubt about the validity or applicability of an advance decision and it is necessary to refer the matter to the Court, then health professionals may provide life-sustaining treatment or treatment that prevents serious deterioration in the patient's condition whilst the decision of the Court is awaited.

3.14 If a patient has made a valid and applicable advance decision to refuse treatment but that treatment is for a mental disorder, a health professional may still give that treatment to the patient if he or she has authority to do so under Part IV and 4A of the Mental Health Act 1983 and consent is not required.

3.15 Further information about advance decisions is available in the Mental Capacity Act Code of Practice.

Other types of advance statements

3.16 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 patient'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.

3.17 As well as an advance statement to refuse treatment, some statements will express the patient'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 interests of the patient³². 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.

Self harm and attempted suicide

3.18 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.

³² R (on the application of Burke) v General Medical Council [2005] EWCA Civ 1003. See also Chapter 4 paragraph 4.40.

- 3.19 If the patient is judged not to have capacity, they may be treated in accordance with the Mental Capacity Act 2005 (see Chapter 2). 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.
- 3.20 However, as noted in paragraphs 3.1 and 3.7 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 (see paragraphs 3.3 to 3.5), 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.

4. Adults Without Capacity

General principles

4.1 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. With effect from 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.

4.2 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 Practice³³ and any person engaged in the care and treatment of an adult who lacks capacity must have regard to this Code.

4.3 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. In practical terms, the Act does not make a significant difference to the way in which professionals made decisions to give treatment before it came into force. As with the common law, they are required to assess whether the patient has capacity and, if not, whether the treatment proposed is in their best interests. Determining a patient's capacity is covered in Chapter 2 above.

³³ See Ministry of Justice website: www.moj.gov.uk.

Best interests

- 4.4 In determining what is in the patient's best interests, the health professional must look at the patient's circumstances as a whole and not just at what is in the patient's 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 patient's past and present wishes and feelings, the beliefs and values that would be likely to influence the patient's decision if they had capacity, and must take account of any other factors that the patient might think relevant
- 4.5 They must also, so far as is practicable and appropriate, take account of the views of any of the following people:
- person who is named by the patient as a person who should be consulted on such matters;
 - the patient's carers or any other person interested in his or her welfare;
 - the person who has been granted a Lasting Power of Attorney by the patient; and
 - any deputy appointed for the patient by the Court.
- 4.6 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.
- 4.7 Lack of capacity will not automatically mean that the patient is unable to participate in the decision making process, and every assistance should be given to enable him or her to do so.
- 4.8 If a patient 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 (See paragraph 4.15)
- 4.9 Where a patient has made an advance statement (see paragraph 3.10) 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 appropriate and not 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

4.10 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. Unless the patient has a valid and applicable advance decision to refuse treatment, then they may be treated insofar as is reasonably required in the patient's best interests pending the recovery of capacity. This will include, but is not limited to, routine procedures such as washing and assistance with feeding. 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

4.11 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 clinical intervention 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 (see paragraph 3.10 – 3.15). If the person does not make any relevant advance decision, the person's treatment when incapacitated should accord with the principles for treating the temporarily incapacitated (paragraph 4.10 above).

Lasting Power of Attorney

4.12 The Mental Capacity Act introduces a new form of power of attorney called a lasting power of attorney (LPA). An LPA may be executed by any person of 18 or over whilst they have capacity and takes effect when they no longer have capacity. An LPA may appoint a person as an attorney to make personal decisions about a person's welfare and medical treatment. An LPA that meets the various legal requirements and is registered with the Office of the Public Guardian may give the attorney power to refuse or consent to any treatment being proposed. 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. 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.

- 4.13 If the patient 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.
- 4.14 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. Any disputes between a health professional and an attorney that cannot be resolved, or cases where there are grounds for believing that the attorney is not making decisions that are in the best interests of the patient, should be referred to the Court of Protection.

Independent Mental Capacity Advocates

- 4.15 If a patient who lacks capacity is to receive serious medical treatment, or arrangements are to be made about their accommodation but that patient has no family or friends to represent and support them, then unless a decision has to be made urgently, an independent mental capacity advocate (“IMCA”)³⁴ must be instructed. The duty to instruct rests with the NHS Trust in the case of accommodation or treatment provided in hospital, or a local authority in the case of residential accommodation.
- 4.16 The role of the IMCA is to represent and support the patient. They will not make decisions on the patient’s behalf and such decisions will still be decided by the professional or hospital managers on the basis of what is in the patient’s best interests. However the IMCA will speak to the patient and, so far as possible, try to engage them in the decision process. They will assist in determining what is in the patient’s best interests and the health professional must take into account the views of the IMCA in deciding what actions to take. They 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.

³⁴ The statutory duty to instruct in 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)).

4.17 Serious medical treatment for this purpose means treatment which involves providing, withdrawing or withholding treatment in circumstances:

- 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 patient³⁵.

Referral to the Court of Protection

4.18 Where there are difficult or complex decisions to make on behalf of a patient who lacks capacity, the matter can be referred to the Court of Protection. Under the Mental Capacity Act the existing Court has been replaced by a new Court of Protection which has wider jurisdiction.

4.19 Health professionals are most likely to involve the Court of Protection where there is a dispute about a patient's capacity to make a decision about a particular type of medical treatment, or whether a patient had capacity when an advance decisions or Lasting Power of Attorney was made. The Court can also make declarations about the lawfulness of a particular course of action such as withdrawing or withholding medical treatment³⁶. It can make orders about a patient's welfare or property and affairs. As with any other person who makes a decision on behalf of the patient, the Court will act in the patient's best interests.

4.20 Where a person lacks capacity then a referral to the Court should always be made in the following circumstances:

- where it is proposed that the patient should undergo non-therapeutic sterilisation (eg. for contraceptive purposes);
- to withdraw nutrition and hydration from a patient in a persistent vegetative state (PVS); or
- there are doubts or is a dispute about whether a particular treatment would be in the best interests of the patient.

³⁵ As defined in the Independent Mental Capacity Act 2005 (Independent Mental Capacity Advocates) (Wales) Regulations 2007 (S.I. 2007/852 (W.77)).

³⁶ For further guidance on declarations that can be made by the Court see Practice Note (Official Solicitor: Declaratory Proceedings: Medical and Welfare Decisions for Adults who lack Capacity) July 2006.

4.21 This is not an exhaustive list and the courts may extend the list of procedures that should always be referred. In other circumstances it may be necessary to refer a matter to the Court where:

- there is a dispute between health professionals, members of the family, partners, carers or any other interested persons such as an Independent Mental Capacity Advocate or the attorney of a Lasting Power of Attorney about what is in the patient's best interests³⁷;
- there is doubt about whether the patient lacks capacity to make a decision for themselves and is not likely to regain capacity in the short term;
- treatment of an experimental nature is proposed.

4.22 The Court has held that therapeutic abortion and sterilisation where there is a medical necessity does not automatically require a referral, although such procedures can give rise to special concern about the best interests and rights of a person who lacks capacity³⁸. In the case of a woman with learning disabilities, it is good practice to involve a consultant in psychiatry of learning disability, the multidisciplinary team and the patient's family/partner as part of the decision-making process and to document their involvement. Less invasive or reversible options should always be considered before permanent sterilisation.

4.23 A health professional who is faced with a situation that may require intervention of the Court of Protection should immediately contact legal advisers. Where an application to the Court is envisaged the Official Solicitor should be contacted³⁹. The duty officer of the Official Solicitor can advise on the appropriate procedure if necessary. The Court has given guidance on making applications to the Court⁴⁰. It is good practice to seek the views of the Court prior to undertaking certain interventions which give rise to particular concern.

4.24 Guidance on referring matters to the Court of Protection has been issued by the General Medical Council and the BMA.

Court appointed deputies

4.25 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

³⁷ In *Glass v UK* (61827/00) [2004] ECHR 102 the ECHR held that failure to refer a matter to the Court in a non emergency situation was a violation of Article 8 (right to private and family life).

³⁸ *D v An NHS Trust (Medical Treatment: Consent: Termination)* (Fam Div) [2004] 1 F.L.R. 1110.

³⁹ The Official Solicitor can be contacted through the Urgent Court Business Officer out of office 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 <http://www.officialsolicitor.gov.uk/>

⁴⁰ See www.publicguardian.gov.uk for further guidance on Court of Protection applications.

normally be family, partners, friends or people who are well known to the patient.

4.26 As with attorneys appointed under a Lasting Power of Attorney, 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.

4.27 Health professionals should co-operate with deputies with the aim of doing what is best for the patient. Where a deputy acting within their authority makes a decision that the patient 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 Public Guardian⁴¹.

Restraint of an incapacitated patient

4.28 In some cases, a patient who lacks capacity may resist treatment and the health professional may need to restrain that patient to administer the treatment. The Mental Capacity Act 2005 provides that a person may lawfully restrain a person who lacks capacity, providing that person believes it is reasonably necessary to prevent harm to the patient, and it is a proportionate response to the likelihood of the patient suffering harm and the seriousness of that harm. Restraint means:

- using, or threatening to use, force to secure the doing of an act which the patient resists; or
- restricting the patient's liberty of movement, whether or not the patient resists.

⁴¹ Reference to contact details for Public Guardian or further information leaflets can be found at www.publicguardian.gov.uk.

4.29 Health professionals should only use restraint where absolutely necessary and should consider the least restrictive means of administering care or treatment. Any act by the health professional that goes beyond restraint could amount to a deprivation of liberty within the meaning of Article 5(1) of the European Convention on Human Rights, which is unlawful.

Deprivation of Liberty

4.30 Patients who lack capacity cannot give consent to be admitted to hospital. In some cases health professionals may consider that it is necessary to keep such patients in hospital, but that it is not appropriate or necessary to detain them under the Mental Health Act 1983 because the patient is compliant. In dealing with these so-called informal patients, health professionals should be aware of the decision of the European Court of Human Rights in *HL v United Kingdom* (sometimes referred to as the “*Bournewood judgement*”)⁴². The European Court held that a patient, who was mentally incapacitated and compliant, had been detained in circumstances that amounted to a deprivation of liberty and this was in violation of Article 5 (right to liberty) of the European Convention of Human Rights. In that case, an autistic man with learning disabilities had been admitted to hospital following an incident at a day centre where he had become particularly agitated. The European Court found that health professionals had exercised complete and effective control over the patient while he was in hospital and had restricted his contact with the outside world, and this amounted to a deprivation of liberty in violation of Article 5.

4.31 Whether a person has been deprived of their liberty, the Court said, would depend on the circumstances of each case. The distinction between a person who is being deprived of liberty or merely restrained, will be the degree or intensity of the restriction and not its nature or substance. In the later case of *DE v Surrey County Council*⁴³, the High Court held that there had been a deprivation of liberty because DE had been detained in a local authority care home and was not free to leave. Although the environment in which he had been detained was not unduly restrictive and he was allowed contact with the outside world, there was a deprivation of liberty because he had repeatedly expressed his wish to return to live with his wife. When his wife attempted to remove him, the manager of the home threatened to call the police to prevent her from doing so (even though the manager was aware that the police had no powers to do this).

4.32 Where an incapacitated patient is detained in hospital, a health professional must care for and treat that patient in the least restrictive way and avoid, so far as is possible, caring for them in a way that

⁴² *HL v United Kingdom* (2005) 40 E.H.R.R.

⁴³ *DE v Surrey County Council* [2006] EWHC 3459

deprives them of their liberty. If it is necessary to deprive the patient of his or her liberty, the NHS Trusts and Local Health Boards should have procedures in place to safeguard the rights of the patient.

- 4.33 The Mental Health Act 2007 inserts new provisions into the Mental Capacity Act 2005 that provide for procedural safeguards for informal patients, and it is anticipated that these provisions will come into force in April 2009. In the meantime health professionals should refer to Welsh Health Circular (2005) 005 Advice on the decision of the European Court of Human Rights in the case of HL v. UK (The “Bournemouth Case”).

Research

- 4.34 Whenever research is proposed on a person who lacks capacity, careful consideration should be given to the ethical and legal requirements of such research. Such requirements are now underpinned by the Mental Capacity Act 2005, which introduces new statutory safeguards for carrying out research on persons who are 16 years and above and lack capacity. Any intrusive research will be unlawful unless it is carried out as part of a research project that has been approved by a recognised independent Research Ethics Committee (REC). All RECs established in England and Wales under the Governance Arrangements for NHS Research Ethics Committees (GfREC) are recognised for this purpose by both the Secretary of State for Health and Welsh Ministers, and are therefore appropriate bodies for the purposes of approving research under the Act. “Intrusive research” means any research that would normally require the consent of a person with capacity in order to be lawful. Before approving a research project, the REC must be satisfied that certain conditions are satisfied. These are:

- that the research is connected with an impairing condition, i.e. a condition which is, or may be attributable to, or which does or may cause or contribute to, disturbance in the functioning of the mind or brain;
- research of comparable effectiveness cannot be carried out using people who have capacity to consent; and
- that it has the potential to benefit the patient without imposing a disproportionate burden on him or her.

- 4.35 If the research does not satisfy the last of these conditions then approval may still be given providing there are reasonable grounds for believing:

- that the risk to the patient from taking part in the project is likely to be negligible; and
- that anything done to, or in relation to, the patient will not:
 - interfere with the patient’s freedom of action or privacy in a significant way; or
 - be unduly invasive or restrictive.

- 4.36 In determining whether the patient should participate in the research, the best interests test will apply. The Act also requires that carers or other persons who have an interest in the patient's welfare must be consulted. If there is no one who can be consulted, then a person who is unconnected with the research project must be appointed to advise on whether the patient should take part in the research. If at any time during the research it appears that the patient is upset or unhappy, it should cease immediately.
- 4.37 A clinical trial is not research for the purposes of the Mental Capacity Act and in such cases the trial should be carried out in accordance with the Medicines for Human Use (Clinical Trials) Regulations 2004⁴⁴, and other regulations relating to clinical trial that may from time to time be in effect.

Withdrawing and Withholding Life-prolonging Treatment

- 4.38 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 assessment 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 patient's best interests. However, in reaching that decision, if it is practical to do so, he or she must consult the patient's relatives, partner, friends, carers or 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 trauma⁴⁵.
- 4.39 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; and, where the patient is in PVS or a state closely resembling PVS, that legal advice should be sought. Further, the courts have stated that it is good practice for court approval to be sought before ANH is withdrawn from patients in PVS.

⁴⁴ S.I. 2004/1031.

⁴⁵ Further guidance is available in a joint statement on "Decisions relating to cardiopulmonary resuscitation (October 2007)" made by the BMA, Resuscitation Council (UK) and the Royal College of Nursing.

4.40 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).

4.41 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."

4.42 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.

4.43 Where the patient has made an advance decision to refuse life-sustaining treatment, then in addition to the usual requirements for a valid 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 paragraph 3.12).

4.44 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

- 4.45 “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”. Updated guidance on the diagnosis of brain stem death is available⁴⁶.
- 4.46 When the diagnosis of brain stem death has been confirmed, all clinical interventions can be withdrawn. If, subject to the requirements of the Human Tissue Act 2004, the deceased person will become an organ donor, medical interventions to facilitate donation, such as maintaining electrolyte balance, may be continued.
- 4.47 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 that artificial ventilation with the sole aim of preserving organ function is unlawful⁴⁷. The purpose of artificial ventilation in these circumstances would not be to benefit the patient and may run the risk of causing serious harm. It is therefore not in the best interests of the patient.

⁴⁶ CMO Wales (98)09: A code of practice for the diagnosis of brain stem death

⁴⁷ DGM (94)116: Identification of potential donors of organs for transplantation

5. Children and Young People

5. This chapter sets out the legal position concerning consent 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.

Young people aged 16 or 17

- 5.1 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. Section 8 does not apply to interventions that do not confer a direct health benefit on the young person such as the donation of organs, blood or other bodily substances (other than for diagnostic purposes).
- 5.2 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. Where an intervention does not fall within 'treatment' for the purposes of section 8, since the Mental Capacity Act came into force the legal position in relation to young people of 16 or 17 years old is unclear. The advice of the Welsh Assembly Government is that the same law should be applied to young people as applies to adults (See Chapter 4). The mental capacity of the patient should be assessed in accordance with the Mental Capacity Act and if that patient has capacity their informed consent should be obtained. A health professional should not rely on parental consent if the patient has capacity. If that patient lacks capacity then the health professional must act in the best interests of the patient (See paragraphs 4.4 to 4.9). Whilst the treatment should not be carried out on the basis of parental consent alone, the views of the person with parental responsibility will be important in determining whether the treatment would be in the patient's best interests.
- 5.3 If a young person with capacity has given valid consent, it is good practice to encourage that person to involve his or her family in the decision-making process, unless it is not appropriate to do so.

- 5.4 Where a young person who has capacity is to be admitted to hospital for treatment for a mental disorder, provisions in the Mental Health Act 2007⁴⁸ (which came into force on 1 January 2008) provide that where that person consents or refuses to be admitted to hospital for treatment for a mental disorder, a person with parental responsibility for that person cannot overrule that consent or refusal.

Competent Children under 16

- 5.5 The case of *Gillick*⁴⁹ 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. Determining whether a child is competent is a question of fact for the court. The courts will consider whether the child is able to reach a mature and balanced judgement, and has sufficient discretion to enable him or her to exercise a wise choice in their own interests. The courts will take into account the child's chronological, mental and emotional age and intellectual development and maturity. A child must not just be able to understand the nature of the advice which is being given, but must also have a sufficient maturity to understand what is involved in the proposed treatment.
- 5.6 The concept of *Gillick* competence is said to reflect the child's increasing development to maturity. 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.
- 5.7 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. 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 support⁵⁰.

⁴⁸ Mental Health Act 2007 (c.12) amends section 131 of the Mental Health Act 1983 (c.20).

⁴⁹ *Gillick v West Norfolk and Wisbech AHA* [1986] AC 112

⁵⁰ *Axon v Secretary of State for Health* [2006] EWHC 37 (Admin).

The requirement of voluntariness

- 5.8 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

- 5.9 Where either a young person of 16 or 17 with capacity or a Gillick competent child under 16, refuses treatment, case law has stated that such a refusal can be over-ruled by a person with parental responsibility for the child⁵¹. However this case pre-dates the Human Rights Act 1998 and the Mental Capacity Act and any health professional faced with these circumstances should exercise extreme caution. It is the Welsh Assembly Government's view that a young person should be treated in the same way as an adult and treatment should not be given on the basis of parental consent.
- 5.10 If it does not cause undue delay that would be detrimental to the patient then in such cases health professionals should seek legal advice and if necessary refer the matter to the Court. The Court may over-rule a child's refusal of treatment particularly where such refusal is likely to lead to the child's death⁵². In the case of NHS Trust v D⁵³ it was stated that "the court's clear respect for the sanctity of human life must impose a strong obligation in favour of taking all steps capable of preserving life, save in exceptional circumstances". Applications to the Court can be made on short notice.
- 5.11 Where a child has refused treatment, if a decision is made to give treatment on the authority of parental consent it must be exercised on the basis that the welfare of the child is paramount⁵⁴. As with the concept of best interests, "welfare" does not just mean physical health but also the impact on the child's mental health will be an important factor, for example where a child is refusing to have an abortion. The psychological effect of having the decision over-ruled must also be considered.
- 5.12 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. In such cases the courts have stated that doubt should be

⁵¹ In Re R (A Minor)(Wardship: Consent to Treatment) [1991] 3 W.L.R. 592

⁵² Re W (A Minor)(Medical Treatment: Court's Jurisdiction) [1992] 3 W.L.R. 758.

⁵³ NHS Trust v D [2000] 2 FLR 677

⁵⁴ See section 1(1)(a) of the Children Act 1989 (c. 41)

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

- 5.13 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 (See Chapter 4). The Act requires that in making decisions any person who has an interest in the welfare of that person must be consulted and their views taken into account. In the case of a young person this is likely to be the parents or any other person with parental responsibility.
- 5.14 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 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. In the case of a child who is under the age of 16, the power to consent must be exercised according to the “welfare principle“: that the child’s “welfare” or “best interests” must be paramount.
- 5.15 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.
- 5.16 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

- 5.17 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.

5.18 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 the birth.

5.19 Where the father is not married to the mother at the time of the birth he can acquire parental responsibility:

- in the case of a child born before 1 December 2003 if he marries the mother of their child or has a parental responsibility order;
- in the case of a child born after 1 December 2003 he is registered on the birth certificate as the child's father⁵⁵, he marries the mother or has a parental responsibility order from the court.

5.20 Persons other than the mother and father who may have parental responsibility are:

- the child's legally appointed guardian;⁵⁶
- a person in whose favour the court has made a residence order concerning the child;
- a Local Authority designated in a 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.

5.21 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 childminder 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.

5.22 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

⁵⁵ Under section 111 of the Adoption and Children Act 2002, 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.

circumcision⁵⁷. This category has now been extended to cover cases that have been described as “hotly contested issues of immunisation”⁵⁸. Where persons with parental responsibility disagree as to whether non-therapeutic procedures are in the child’s best interests, it is advisable to refer the decision to the courts. 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, although such a case has not yet been considered by the courts in England and Wales. 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.

- 5.23 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.
- 5.24 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.
- 5.25 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. Where abuse or neglect is suspected then health professionals should act in accordance with guidance in *Working Together to Safeguard Children*⁵⁹.
- 5.26 If a child is a ward of court, no important decision may be taken without the prior consent of the court. This is likely to include significant medical interventions but not treatment for minor injuries or common diseases of childhood.

Person with parental responsibility refusing consent

- 5.27 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.

⁵⁷ Re J (A Minor) (Prohibited Steps Order: Circumcision) [2000] 1 FLR 571 at 577. Female circumcision is always prohibited, under the *Prohibition of 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 two of the ‘Green Book’ published by the Department of Health.

⁵⁹ *Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children* HM Government 2006.

⁶⁰ See Re Wyatt (A Child) (Medical Treatment: Continuation of Order) [2005] 2 F.L.R. 480.

5.28 In the event of a disagreement about treatment between persons with parental responsibility and the health professionals and this cannot be resolved, the Court should be involved unless it is an emergency situation. The decision by the European Court of Human Rights in the case of *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 Human Rights Act. All NHS Trusts should have procedures for dealing with such circumstances.

Research

5.29 For young people who are 16 or 17, the Mental Capacity Act will apply in determining their capacity for the purposes of giving consent to take part in a research project. If the young person is found not to have capacity, then the safeguards as set out in the Mental Capacity Act 2005 in relation to research will apply (see paragraphs 4.34 – 4.37).

5.30 Where the child is under the age of 16, he or she may be competent to give consent, although there are complex legal and ethical considerations that the health professional should be aware of when deciding whether it is appropriate for the child to take part in the research⁶². It is good practice for parental consent to be obtained as well as obtaining consent from a competent child. However, research should not be undertaken if parental consent is given but the person with parental responsibility is not acting in the best interests of the child. Where parental consent has been given but the child has refused, then health professionals should only continue with the research in exceptional circumstances and take legal advice before doing so.

5.31 Although there is no directly relevant case law on the issue of children participating in research that involves experimental or innovative treatment, the court has considered this in the relation to incompetent adults. In *Simms v Simms*⁶³ the court was prepared to sanction the treatment providing certain criteria were satisfied, and it is helpful for health professionals to consider these criteria when contemplating such treatment on a child. These are that:

- the patient did not have the mental capacity to make the decision about the treatment his or herself;
- the treatment proposed came within the Bolam⁶⁴ test in that a reasonable body of medical opinion would support the treatment within the United Kingdom;
- it was in the best interests of the patient that the treatment should be given; and

⁶¹ *Glass v United Kingdom* [2004] 1 F.L.R. 1019.

⁶² Royal College of Paediatrics and Child Health, Ethics Advisory Committee; Guidelines for the Ethical Conduct of Medical Research Involving Children (2000).

⁶³ *Simms v Simms* [2003] Fam 83.

⁶⁴ *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582

- the treatment proposed was capable of being carried out within the NHS.

5.32 Where the research is not directly beneficial to the child, it can be compatible with the best interests requirement providing the research causes minimal burden to the child in terms of its invasiveness and intrusiveness.

Vaccination and Immunisation

5.33 Advice on gaining consent for the immunisation and vaccination of children is given in the '*Green Book*' published by the Department of Health.⁶⁵ 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 clinical advice.

5.34 Immunisation practitioners and health professionals are advised not to accept the action of attendance at the clinic as reconfirmation of consent for the immunisation to be given. Reconfirmation of consent should be sought verbally⁶⁶.

Using children lacking capacity as bone marrow donors

5.35 Donation of bone marrow can be painful and carries some significant risks. Normally it will not be appropriate for a child lacking capacity to be a bone marrow donor. However in some cases their bone marrow may be a match and will assist in the treatment of a sibling. Any decision of this nature should still be justified in the best interests and welfare of the child. However the Court has held that by prolonging the life of a sibling a person would receive emotional, psychological and social benefit. However, the Court also considered the particular circumstances under which the intervention would take place and came to the view that it would be of minimal detriment to the person compared with the benefits she would receive⁶⁷.

5.36 Since September 2006 the donation of bone marrow by any child who lacks competence requires prior approval from the Human Tissue Authority having first been assessed by an Accredited Assessor⁶⁸.

⁶⁵ www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Greenbook/DH_4097254

⁶⁶ See also Welsh Health Circular (2006) 052 Consent for School Dental Inspections and Dental Epidemiology Inspections.

⁶⁷ *Y* (Mental Patient: Bone Marrow Donation) [1997] Fam. 110.

⁶⁸ Guidance can be found in HTA's Code of Practice on "Donation of allogeneic bone marrow and peripheral blood stem cells for transplantation."

Children and Confidentiality

- 5.37 If a child is competent to consent to treatment then the clinician will owe the same duty of confidence to the child as he or she would to an adult and that child's confidence must be respected. However, where a parent wishes to overrule a competent child's refusal, then in order to make such a decision, he or she must inevitably be provided with sufficient information about their child's condition, which the child may not be willing for them to receive. If a clinician gives information to the parent in these circumstances, then this may constitute a breach of confidence by the clinician. However, such a breach of confidence may be justified if it is in the child's best interests particularly if the treatment proposed is for a life threatening condition. In making any decision to disclose information, clinicians should be aware that the Welsh Assembly 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.
- 5.38 If a child does not have capacity 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.