INFORMATION TO ASSIST IN AMENDING CONSENT FORMS

The following suggestions may help Trusts who have not already done so to amend their consent forms in the light of legislative and other changes. This is not a comprehensive list of all changes that Trusts may wish to make, which will be a matter for local decision. Trusts may wish to consult their own legal Departments about the suitability of their forms.

There are some global changes that can be made to the wording of the forms to reflect the Mental Capacity Act (MCA), most significantly the use of 'capacity' or 'lack the capacity' in place of 'competent' and the term 'advance decision to refuse treatment' in place of 'advance directive' or 'living will'.

Trusts may also want to include a reference to consent for the use of human tissue under the Human Tissue Act on some of the forms as appropriate.

The completion of consent forms is of course only part of the consent process and should only be carried out in the context of an informed discussion with the person giving consent with more detailed explanation given where necessary.

Consent form 1 – Patient agreement to investigation or treatment

- This form deals with people who have the capacity to consent to treatment and therefore is largely unaffected by the MCA.

- In the section 'statement of health professional', the wording about risks could be amended to reflect the *Chester v Afshar* judgment (see introduction of revised Reference guide to consent),. so as to prompt health professionals to discuss "significant, unavoidable or frequently occurring risks" with the patient rather than simply recording "serious or frequently occurring risks" as at present.

- The information on page 4 could be updated to reflect the MCA, in particular the section on when the form would not be used, which could be amended in the following way:

"When NOT to use this form

If the patient is 18 or over and lacks the capacity to give consent, you should use form 4 (form for adults who lack the capacity to consent to investigation or treatment) instead of this form. A patient lacks capacity if they have an impairment of the mind or brain or disturbance affecting the way their mind or brain works and they cannot:

- understand information about the decision to be made
- retain that information in their mind
- use or weigh that information as part of the decision-making process, or
- communicate their decision (by talking, using sign language or any other means).

You should always take all reasonable steps (for example involving more specialist colleagues) to support a patient in making their own decision, before concluding that they are unable to do so.

Relatives **cannot** be asked to sign a form on behalf of an adult who lacks capacity to consent for themselves, unless they have been given the authority to so under a Lasting Power of Attorney or as a court appointed deputy."

Consent form 2 - Parental agreement to investigation or treatment for a child or young person

- It may be useful to amend the title of the form and other reference to a parent to read 'parent (or person who has parental responsibility)'

- The section 'statement of health professional' – the wording about risks could be amended to reflect the *Chester v Afshar* judgment (see introduction of revised Reference guide to consent) for example to prompt health professionals to discuss "significant, unavoidable or frequently occurring risks" with the patient rather than simply recording "serious or frequently occurring risks" as at present.

- The information 'who can consent' on page 4 could be amended where it refers to young people who refuse consent (see 'Child or young person with capacity refusing treatment' in Chapter 3 of revised Reference guide to consent). The text could be amended along the following lines:

"Where a young person of 16 or 17 or a Gillick competent child under 16, refuses treatment, it is possible that such a refusal could be over-ruled if it would in all probability lead to the death of the child or to severe permanent injury. It would be prudent, to obtain a court declaration or decision if faced with a competent child or young person who is refusing to consent to treatment, to determine whether it is lawful to treat the child."

Consent form 3 - Patient/parental agreement to investigation or treatment

- Comments on use of terms and amendments to reflect the *Chester v Afshar* judgment as for forms 1 and 2 would also apply to this form.

Consent form 4 - Form for adults who are unable to consent to investigation or treatment

- The MCA is of most relevance to this form and this is covered in chapter 2 of the revised Reference guide to consent.
- It may be useful to amend the title of the form to 'Form for adults who lack the capacity to consent to investigation or treatment'
- Section B will need to be amended to reflect the wording of the MCA, for example along the lines of:

"B Assessment of patient's capacity (in accordance with the Mental Capacity Act)

I confirm that the patient lacks capacity to give or withhold consent to this procedure or course of treatment because of an impairment of the mind or brain or disturbance affecting the way their mind or brain works (for example, a disability, condition or trauma, or the effect of drugs or alcohol) and they cannot do one or more of the following:

□ understand information about the procedure or course of treatment
□ retain that information in their mind
□ use or weigh that information as part of the decision-making process, or
□ communicate their decision (by talking, using sign language or any other means)

Further details: for example how above judgements reached; which colleagues consulted; what attempts made to assist the patient make his or her own decision and why these were not successful."

- Section C will need to reflect the elements health professionals will need to consider as part of a best interests assessment, for example along the following lines:

"C Assessment of patient's best interests

I am satisfied that the patient has not refused this procedure in a valid advance decision. As far as is reasonably possible, I have considered the person's past and present wishes and feelings (in particular if they have been written down) any beliefs and values that would be likely to influence the decision in question. As far as possible, I have consulted other people (those involved in caring for the patient, interested in their welfare or the patient has said should be consulted) as appropriate. I have considered the patient's best interests in accordance with the requirements of the Mental Capacity Act and believe the procedure to be in their best interests because:

(Where the lack of capacity is likely to be temporary ……..)

The treatment cannot wait until the patient recovers capacity because: "

- Section D will need to reflect the fact that, unless the person has an attorney or deputy, the final responsibility for determining what is in a person's best interest will rest with the relevant health professional. However, the health professional must consult with those close to the patient (eg spouse/partner, family and friends, carer, supporter or advocate) as far as is practicable and as appropriate.

- Section D could also include a section on the involvement of an Independent Mental Capacity Advocate, for example along the lines of:

"Independent Mental Capacity Advocate (IMCA)
For decisions about serious medical treatment, where there is no one appropriate to consult other than paid staff, has an Independent Mental Capacity Advocate (IMCA) been instructed?

□ Yes □ No

Details:

Signature …….. Date……..."

- The form could include a new section E to cover patients who have an attorney or deputy, for example along the lines of:

E The patient has an attorney or deputy

Where the patient has authorised an attorney to make decisions about the procedure in question under a Lasting Power of Attorney or a Court Appointed Deputy has been authorised to make decisions about the procedure in question, the attorney or deputy will have the final responsibility for determining whether a procedure is in the patient's best interests.

Signature of attorney or deputy

I have been authorised to make decisions about the procedure in question under a Lasting Power of Attorney / as a Court Appointed Deputy (delete as appropriate). I have considered the relevant circumstances relating to the decision in question (see section C) and believe the procedure to be in the patient's best interests.

Any other comments (including the circumstances considered in assessing the patient's best interests)

Signature:…….…… etc"

- The information on page 4 will need to be amended in line with the changes made to the form and the MCA. The information below is given as a guide of the areas this information could cover:

"Guidance to health professionals

This form should only be used where it would be usual to seek written consent but an adult patient (16 or over) lacks capacity to give or withhold consent to treatment. If an adult **has** capacity to accept or refuse treatment, you should use the standard consent form and respect any refusal. Where treatment is very urgent (for example if the patient is critically ill), it may not be feasible to fill in a form at the time, but you should document your clinical decisions appropriately afterwards. If treatment is being provided under the authority of Part IV of the *Mental Health Act 1983*, different legal provisions apply and you are required to fill in more specialised forms (although in some circumstances you may find it helpful to use this form as well). If the adult now lacks capacity, but has made a valid advance decision to refuse treatment that is applicable to the proposed treatment then you must abide by that refusal.. For further information on the law on consent, see the Department of Health's *Reference guide to consent for examination or treatment* (www.dh.gov.uk/consent).

When treatment can be given to a patient who lacks the capacity to consent
All decisions made on behalf of a patient who lacks capacity must be made in accordance with the Mental Capacity Act 2005. More information about the Act is given in the Code of Practice[1]. Treatment can be given to a patient who is unable to consent, only if :

- the patient lacks the capacity to give or withhold consent to this procedure AND
- the procedure is in the patient's best interests.

Capacity
A person lacks capacity if they have an impairment or disturbance (for example, a disability, condition or trauma, or the effect of drugs or alcohol) that affects the way their mind or brain works which means that they are unable to make a specific decision at the time it needs to be made. It does not matter if the impairment or disturbance is permanent or temporary. A person is unable to make a decision if they cannot do one or more of the following things:

- Understand the information given to them that is relevant to the decision.
- Retain that information long enough to be able to make the decision.
- Use or weigh up the information as part of the decision- making process.

[1] Mental Capacity Act 2005 Code of Practice - www.publicguardian.gov.uk/mca/code-of-practice.htm

- Communicate their decision - this could be by talking or using sign language and includes simple muscle movements such as blinking an eye or squeezing a hand.

You must take all steps reasonable in the circumstances to assist the patient in taking their own decisions. This may involve explaining what is involved in very simple language, using pictures and communication and decision-aids as appropriate. People close to the patient (spouse/partner, family, friends and carers) may often be able to help, as may specialist colleagues such as speech and language therapists or learning disability teams, and independent advocates (as distinct from an IMCA as set out below) or supporters. Sometimes it may be necessary for a formal assessment to be carried out by a suitably qualified professional.

Capacity is 'decision-specific': a patient may lack capacity to take a particular complex decision, but be able to take other more straight-forward decisions or parts of decisions. Capacity can also fluctuate over time and you should consider whether the person is likely to regain capacity and if so whether the decision can wait until they regain capacity.

Best interests

The Mental Capacity Act requires that a health professional **must** consider all the relevant circumstances relating to the decision in question, including, as far as possible considering:

- the person's past and present wishes and feelings (in particular if they have been written down)
- any beliefs and values (e.g. religious, cultural or moral) that would be likely to influence the decision in question and any other relevant factors
- the other factors that the person would be likely to consider if they were able to do so.

When determining what is in a person's best interests" a health professional must not make assumptions about someone's best interests merely on the basis of the person's age or appearance, condition or any aspect of their behaviour. If the decision concerns the provision or withdrawal of life-sustaining treatment the health professional must not be motivated by a desire to bring about the person's death.

The Act also requires that, as far as possible, health professionals must consult other people, if it is appropriate to do so, and take into account of their views as to what would be in the best interests of the person lacking capacity, especially anyone previously named by the person lacking capacity as someone to be consulted and anyone engaging in caring for patient and their family and friends.

Independent Mental Capacity Advocate (IMCA)

The Mental Capacity Act introduced a duty on the NHS to instruct an independent mental capacity advocate (IMCA) in serious medical treatment decisions when a person who lacks capacity to make a decision has no one who can speak for them, other than paid staff. IMCAs are not decision makers for the person who lacks capacity. They are there to support and represent that person and to ensure that decision making for people who lack capacity is done appropriately and in accordance with the *Act*.

Lasting Power of Attorney and Court Appointed Deputy

A person over the age of 18 can appoint an attorney to look after their health and welfare decisions, if they lack the capacity to make such decisions in the future. Under a Lasting Power of Attorney (LPA) the attorney can make decisions that are as valid as those made by the person themselves. The LPA may specify limits to the attorney's authority and the LPA must specify whether or not the attorney has the authority to make decisions about life-sustaining treatment. The attorney can only, therefore, make decisions as authorised in the LPA and must make decisions in the person's best interests.

The Court of Protection can appoint a deputy to make decisions on behalf of a person who lacks capacity. Deputies for personal welfare decisions will only be required in the most difficult cases where important and necessary actions cannot be carried out without the court's authority or where there is no other way of settling the matter in the best interests of the person who lacks capacity. If a deputy has been appointed to make treatment decisions on behalf of a person who lacks capacity then it is the deputy rather than the health professional who makes the treatment decision and the deputy must make decisions in the patient's best interests.

Second opinions and court involvement

Where treatment is complex and/or people close to the patient express doubts about the proposed treatment, a second opinion should be sought, unless the urgency of the patient's condition prevents this. The Court of Protection deals with serious decisions affecting personal welfare matters, including healthcare, which were previously dealt with by the High Court. Cases involving:

- decisions about the proposed withholding or withdrawal of artificial nutrition and hydration (ANH) from patients in a permanent vegetative state (PVS)
- cases involving organ, bone marrow or peripheral blood stem cell (PBSC) donation by an adult who lacks capacity to consent
- cases involving the proposed non-therapeutic sterilisation of a person who lacks capacity to consent to this (e.g. for contraceptive purposes) and
- all other cases where there is a doubt or dispute about whether a particular treatment will be in a person's best interests (include cases involving ethical dilemmas in untested areas)

should be referred to the Court for approval. The Court can be asked to make a decision in cases where there are doubts about the patient's capacity and also about the validity or applicability of an advance decision to refuse treatment.