A Short Guide to the *Mental Capacity Act 2005* and Code of Practice

Introduction

The Mental Capacity Act 2005, covering England and Wales, provides a statutory framework for people who lack capacity to make decisions for themselves, or who have capacity and want to make preparations for a time when they may lack capacity in the future. It sets out who can take decisions, in which situations, and how they should go about this. The Act came into force during 2007. The equivalent legislation for Scotland is the Adults with Incapacity (Scotland) Act.

The legal framework provided by the Mental Capacity Act 2005 is supported by a Code of Practice (the Code). The Code has statutory force, which means that certain categories of people have a legal duty to have regard to it when working with or caring for adults who may lack capacity to make decisions for themselves. These categories include anyone who is:

- an attorney under a Lasting Power of Attorney (LPA)
- a deputy appointed by the new Court of Protection
- acting as an Independent Mental Capacity Advocate (IMCA)
- **carrying out research approved in accordance with the Act**
- acting in a professional capacity for, or in relation to, a person who lacks capacity
- being paid for acts for, or in relation to, a person who lacks capacity.

If you wish to conduct research with adults who lack capacity you **must** consult the Mental Capacity Act and be guided by the associated Code of Practice. These can be found at:

Act: http://www.legislation.gov.uk/ukpga/2005/9/contents

Code: http://webarchive.nationalarchives.gov.uk/+/http://www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf

You may also find this resources useful:

The Mental Capacity Act – Fact Sheet for Social Scientists

Research covered by the Mental Capacity Act must be approved by an “appropriate body”. In England, the appropriate body must be a Research Ethics Committee recognised by the Secretary of State. You will need to find out who the appropriate body is for your proposed research but this is likely to be a Social Care Research Ethics Committee.

Details of this committee can be found at: http://www.screc.org.uk/

Definitions within the act

Below is a short guide to help define some of the key terms in the Act and the Code

Capacity

Whenever the term ***a person who lacks capacity*** is used, it means a person who lacks capacity to make a particular decision or take a particular action for themselves at the time the decision or action needs to be taken. This reflects the fact that people may lack capacity to make some decisions for themselves, but will have capacity to make other decisions.

For example, they may have capacity to make simple decisions about what to wear or what to eat, but lack capacity to make more complex decisions about financial matters.

It also reflects the fact that a person who lacks capacity to make a decision for themselves at a certain time, may be able to make that decision at a later date. This may be because they have an illness or condition that means their capacity changes.

It also reflects the fact that while some people may always lack capacity to make some types of decisions, others may learn new skills that enable them to gain capacity and make decisions for themselves.

Research

The Act does not have a specific definition for research, but uses the Department of Health and National Assembly for Wales publication, *Research Governance Framework For Health And Social Care* which states:

> *research can be defined as the attempt to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods.*

It is expected that most of the researchers who ask for their research to be approved under the Act will be medical or social care researchers. However, the Act can cover more than just medical and social care research. It applies to research that:

- is ***intrusive*** (i.e. if a person taking part had capacity, the researcher would need to get their consent to involve them)
- involves people who have an impairment of, or a disturbance in the functioning of, their mind or brain which makes them unable to decide whether or not to agree to take part in the research (i.e. they lack capacity to consent), and
- is not a clinical trial covered under the Medicines for Human Use (Clinical Trials) Regulations 2004.

Statutory Principles in relation to Capacity to Consent

The Act sets out five statutory principles:

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success.

3. A person is not to be treated as unable to make a decision merely because they make an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in their best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Before deciding that someone lacks capacity to make a particular decision, it is important to take all practical and appropriate steps to enable them to make that decision themselves.

Assessing capacity

Anybody who claims that an individual lacks capacity should be able to provide proof. They need to be able to show, *on the balance of probabilities*, that the individual lacks capacity to make a particular decision, at the time it needs to be made. To help determine if a person lacks capacity to make particular decisions, the Act sets out a two-stage test of capacity.

Stage 1: Does the person have an impairment or a disturbance?

Stage 2: Does the impairment or disturbance mean that the person is unable to make a specific decision when they need to?

Anyone assessing a person's capacity to make a decision for themselves should use the two-stage test of capacity. Further details are found in the Code about who should do this, but the usual principle is that it should not be a paid professional person unless the prospective participant has no one close to them that can do this, or the decision is particularly complex. There is clear guidance in the Code to help you identify when this might be necessary and who might be an appropriate person.

People with fluctuating or temporary capacity

Some people have fluctuating capacity. For example, someone with bipolar disorder may experience a temporary phase which causes them to lack the capacity to make certain decisions.

It may be possible to put off the decision until the person has the capacity to make it. Guidance on how to support someone with fluctuating or temporary capacity, and who should be involved, is found in the Code.

Best interest

A key principle of the Act is that any act done for, or any decision made on behalf of a person who lacks capacity, must be done, or made, in that person's *best interests*. There are exceptions to this, including circumstances where a person has made an advance decision to refuse treatment and, in specific circumstances, the involvement of a person who lacks capacity in research (see chapter 11 of the Code). But otherwise the underpinning principle of the Act is that all acts and decisions should be made in the best interests of the person without capacity.

Wherever possible, the person who lacks capacity to make a decision, should be involved in the decision-making process. Their involvement can help work out what would be in their best interests.

Advance Decision

People who are aged 18 or over can make an advance decision under the Act if they have the capacity to make the decision. They must say what treatment they want to refuse, and they can cancel their decision – or part of it – at any time.

Research-specific issues in the Code of Practice

What assumptions can a researcher make about capacity?

The assumptions a researcher makes are the same as those for treatment, i.e. that a person must be assumed to have capacity unless it is established that they lack capacity and should not be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success.

Who is responsible for making sure the research meets the Act's requirements?

Responsibility for meeting the Act's requirements lies with the "appropriate body", as defined in regulations made by the Secretary of State (for regulations applying in England) or the National Assembly for Wales (for regulations applying in Wales) and the researchers carrying out the research.

How can research get approval?

Research covered by the Act cannot include people who lack capacity to consent to the research, unless it has the approval of the "appropriate body" and it follows other requirements in the Act. In England, the "appropriate body" must be a research ethics committee recognised by the Secretary of State.

Research must also meet one of two requirements:
1. The research must have some chance of benefiting the person who lacks capacity. The benefit must be in proportion to any burden caused by taking part, or
2. The aim of the research must be to provide knowledge about the cause of, treatment of, or care of people with the same impairing condition – or a similar condition.

If researchers are relying on the second requirement, the Act sets out further requirements that must be met:

- the risk to the person who lacks capacity must be negligible
- there must be no significant interference with the freedom of action or privacy of the person who lacks capacity, and
- nothing must be done to, or in relation to, the person who lacks capacity which is unduly invasive or restrictive

What responsibilities do researchers have?

Before starting the research, the research team must make arrangements to:
obtain approval for the research from the "appropriate body"
- get the views of any carers and other relevant people before involving a person who lacks capacity in research
- respect the objections, wishes and feelings of the person, and

- place more importance on the *person's* interests than on those of science and society.

How far should researchers consult with carers or other consultees?

Once it has been established that a person lacks capacity to agree to participate, then, before they are included in research, the researcher must consult with specified people in accordance with section 32 of the Act to determine whether the person should be included in the research.

The researcher should as a matter of good practice take reasonable steps to identify someone to consult. That person (the consultee) must be involved in the person's care, interested in their welfare and must be willing to help. They must not be a professional or paid care worker. They will probably be a family member, but could be another person.

Researchers must take into account previous wishes and feelings that the person might have expressed about who they would, or would not, like involved in future decisions.

What if a person has capacity when the research starts but loses capacity?

Some people with capacity will agree to take part in research but then lose capacity before the end of the project. In this situation, researchers will be able to continue research as long as they comply with the conditions set out in the Mental Capacity Act 2005 (Loss of Capacity During Research Project) (England) Regulations 2007.
What other safeguards does the Act require?

Even when a consultee agrees that a person can take part in research, the researcher must still consider the person's wishes and feelings. Researchers must not do anything the person who lacks capacity objects to. They must not do anything to go against any advance decision to refuse treatment, or any other statement the person has previously made, expressing preferences about their care or treatment. They must assume that the person's interests in this matter are more important than those of science and society.

A researcher must withdraw someone from a project if:
- they indicate in any way that they want to be withdrawn from the project (for example, if they become upset or distressed), or
- any of the Act's requirements are no longer met.