Supplementary data

This supplementary data comprises two appendices, and a figure that outlines the main themes considered in the paper.

Appendix one is a brief report on the early published papers and research concerned with Mental Capacity, with reference to eight papers published between 1946 and 1988.

Appendix two gives suggested points that should be documents after a decision has been made about a person’s mental capacity, in two circumstances:

- When the decision is relatively straightforward, and there is unlikely to be any doubt or disagreement.
- When the decision is more difficult or finely-balanced, and doubt or disagreement is likely.

The tables give suggested headings, with brief comments.

Figure one outlines the content of the paper. It does not and cannot include all the details or much specific definition. The paper should be read in order to appreciate some of the complexities and nuances associated with the concept of Mental Capacity, and to appreciate the evidence available.
Appendix one

An overview of early (up to 1988) published papers on Mental Capacity.

This is a non-systematic review of historical research into the concept of mental capacity and its assessment. It considers papers published before 1988 when a major paper was published, [1] probably based on a book published in 1987. [2]

The primary search was in EMBASE, Medline, and PsychINFO using two searches:
- (patient consent capacit*).ti,ab [DT 1946-1988] (n = 24)
- (decision competen* patient).ti,ab [DT 1946-1988] (n = 95)

In the first half of the twentieth century patients generally accepted a doctor’s decision, advice or treatment unquestioningly. Concerns about a patient’s ability to understand and agree to treatments did not arise. The unethical medical and research practices in the mid-twentieth century precipitated a move towards greater patient involvement in and agreement to both research and treatments.

In the United States the move towards seeking informed consent to treatment started in the mid-fifties, apparently following a legal case. [3] The difficulties that some people had in understanding information and/or reaching a decision using the information was soon recognised. This concern covered both patients with formal psychiatric conditions, and patients with cognitive problems. This appendix will not consider papers relating specifically to people with a designated mental illness.

The first paper of note seems to have been in 1977 when a review of factors needed to give informed consent was published. [4] The components needed for fully informed consent started with a pre-condition that the decision was voluntary, and not influenced by others. The other three components were the provision of information, the “patient’s competency and understanding”, and communication of the decision.

The review [4] noted that there were two ways of validating a decision as being competent. The first was congruence with a reasonable person’s decision, a method proposed by others. [5] The second was based on the person having reasonable cognitive power, simply ensuring that the person had understood the information. This approach was associated with an early call to develop “a cognitive screening instrument to assess the individual’s capacity to make an informed decision.” [6]

In the 1980s the question of not treating or withdrawing treatment from people with severe and intractable illnesses was also being discussed, including when people lacked capacity, and those papers also commented on the assessment of capacity. For example, one paper [7] said “There are three basic prerequisites for informed consent: the patient must have
the capacity to reason and make judgments, the decision must be made voluntarily and without coercion, and the patient must have a clear understanding of the risks and benefits of the proposed treatment alternatives or nontreatment, along with a full understanding of the nature of the disease and the prognosis.”

In 1982, a paper set out both three general aspects of making an informed decision, [8] with some specific ideas on how the third aspect, a patient’s competence, could be judged:

- Freedom to make a choice
- Materiality, the provision of all necessary information in an understandable way
- Competency, which was judged against four standards:
  - Assent (expressing agreement) which seems to imply being voluntary
  - Capacity to understand the nature and consequences of the decision
  - Rational manipulation of the information
  - Appreciation of the present situation.

Conclusion.
This brief overview shows that:

- Involvement of patients in healthcare decisions started in the mid-1950s
- The initial development of interest in the topic of mental capacity, initially referred to a competence, started in the mid-1970s;
- Research into and discussion about mental capacity has been active for many years;
- The difficulties in conceptualisation of mental capacity has remained the same:
  - How to categorise its components; and
  - How to set criteria to determine the presence or absence of capacity.
References.


### Appendix two

Summary form for documenting straightforward capacity decisions.

<table>
<thead>
<tr>
<th>Heading</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decision(s)</td>
<td>This should give the specific decision and/or the range of decisions covered</td>
</tr>
<tr>
<td>Cause</td>
<td>This should identify the condition that has caused the concern about a lack of capacity, even if the person is thought to have capacity</td>
</tr>
<tr>
<td>Capacity</td>
<td>This states the conclusion: has capacity, does not have capacity, uncertain about capacity</td>
</tr>
<tr>
<td>Evidence</td>
<td>This should give sufficient evidence to explain the conclusion reached. In complex cases more detail should be given - see second form</td>
</tr>
<tr>
<td>Future</td>
<td>This should indicate prognosis for capacity - both possibility of recovery and possibility of loss - and when or whether it should be re-assessed.</td>
</tr>
<tr>
<td>Action</td>
<td>This should specify any action undertaken, such as organising a best interests meeting or a detailed assessment. If no action needed, say so.</td>
</tr>
</tbody>
</table>
### Mental Capacity – supplementary data

#### Detailed form for documenting more complex decisions only

<table>
<thead>
<tr>
<th>Heading</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decision(s):</td>
<td>This should specify the decision(s) being considered in sufficient detail to allow a clear understanding of the issues and evidence given.</td>
</tr>
<tr>
<td>Facts given:</td>
<td>This should outline the major groups of facts given, and what they were</td>
</tr>
<tr>
<td>Cause:</td>
<td>This should give sufficient detail of the nature and extent of the neurological damage and/or dysfunction to allow evaluation of whether it justifies the conclusion</td>
</tr>
<tr>
<td>Capacity:</td>
<td>This should give the final judgment made about capacity. If more than one decision was being considered, then it should make clear which the patient did and did not have the capacity to make.</td>
</tr>
<tr>
<td>Competing</td>
<td>This should record any potential competing interests of any person contributing to the decision about capacity.</td>
</tr>
<tr>
<td>influences</td>
<td></td>
</tr>
<tr>
<td>Evidence:</td>
<td>This should be sufficient to justify the judgment, and should include specific examples or details. It must cover:</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>a) <strong>Understanding.</strong> Is the person able to paraphrase the information given with reasonable accuracy? Do they appreciate that they are making a decision against their own criteria, not simply agreeing with what is suggested? In many cases, presenting the information on paper or in diagrams, or other ways should help.</td>
<td></td>
</tr>
<tr>
<td>b) <strong>Remembering.</strong> Is the person still in possession of all information when making their decision? In many cases it should be possible to overcome forgetfulness using notes, or other similar aids.</td>
<td></td>
</tr>
</tbody>
</table>
c) **Weighing.** Is there evidence that the person has used the facts and their own system of values to reach a conclusion? Is there evidence that they have actually relied on or been influenced by other factors not reflecting the facts and/or their values. For example, delusions or pressure from others. It is best established by asking the person to explain their reasoning.

d) **Communicating.** Can the person communicate their decision? Is the decision communicated in a clear and dependable way, or does it require interpretation by an observer?

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**Future:**
This should cover the likelihood that the person may recover (or lose) capacity, or may fluctuate into or out of having capacity. It should also specify, in people judged to lack capacity, whether any intervention might improve their capacity sufficiently to make a valid decision.

**Action:**
This should specify all consequent actions, including if appropriate when capacity should be reviewed formally.

**Person/people involved**
The names and job roles of all people should be documented to allow the reader to judge for themselves (a) competence and experience and (b) potential significant bias.