

Marie Curie Cancer Care Research Programme - Project Grant

Project details
<p>Dr Catherine Evans (PI), King's College London</p> <p>Mental capacity and processes of informed consent for research on end of life care</p> <p>Duration of project: 19 months Proposed start date: 1 October 2011 (TBC) Budget: £97,603</p>

Abstract
<p>Background A major barrier to improving End of Life Care (EoLC) for people with cancer and non-cancer groups is the inclusion of those near to death in research studies on care and treatment. It is essential to include those at the end of life to understand how to provide the best support and care. The Mental Capacity Act 2005 (MCA) clarified concepts that could inform the development of processes of consent for patients with declining capacity associated with nearness to death. There are examples of innovative approaches, but uncertainty surrounds how these innovations could enable the inclusion of patients nearing death in research studies. Determining the best ways to include those near to death in research on EoLC could greatly strengthen the evidence base.</p> <p>Aim To determine how best to include individuals near to death in research on EoLC by identifying solutions and developing best practice guidance on processes of consent for people with impaired mental capacity.</p> <p>Objectives To examine perspectives of researchers, patients and carers on the challenges experienced to recruit individuals with declining capacity to research studies. To identify in research studies the solutions used to manage processes of consent for individuals with impaired capacity. To obtain a consensus on the priority of the solutions proposed to facilitate processes of consent. To develop best practice guidance on processes of consent for participants with impaired, or declining, capacity to consent themselves.</p> <p>Methods The research plan uses a two phase design. Phases 1a and 1b are simultaneous.</p> <p>Phase 1a: A literature appraisal asking 'What solutions to processes of consent have research studies incorporated to enable the inclusion of individuals with declining mental capacity? We will use narrative synthesis to systematically review and synthesise the literature on processes of consent and mental capacity across a range of conditions.</p> <p>Phase 1b: We will consult stakeholders (e.g. research ethics committee members) on solutions to include individuals with impaired capacity using the Transparent Expert Consultation then the Nominal Group Technique. Preliminary synthesis of the phase 1 findings will form the 1st draft of the best practice guidance.</p> <p>Phase 2: An expert 'think tank' workshop will critically consider this draft by discussing the solutions proposed and contentious issues. We will develop the Methods Guidance from a final synthesis of the findings.</p> <p>How the results will be used This project will develop for academics and ethics committee members best practice guidance on the inclusion of individuals with impaired capacity associated with nearness to death in research on EoLC.</p>