Supplementary Material 1 – Consent Flow charts (patients with capacity)

Flow chart 1: Initial approach to patient and family when patient has capacity

Code numbers in parentheses indicate relevant information sheet, consent form or letter

Patient referred to ICU (therefore decision-making process is eligible as a study index case)

Agreement sought from patient for presence of researcher. (researcher leaves if agreement withheld)

In first 48 hrs ICU or ICU outreach informs patient of research (verbal information with leaflet to keep: PIS1) and seeks verbal agreement for the researcher to speak to the patient’s family.

Patient agrees to family contact
Researcher approaches family and asks if they agree to a brief interview (PIS2)

Family track and when on ward approached by researcher with a reminder about the study. Retrospective written consent sought for family interview data to be used and family to be contacted for follow up interview (PIS2, PCF1)

Patient refuses: Family data withdrawn from analysis
Patient consents: See Flow chart 4
Contact details obtained: See Flow chart 4
Refused: No further family follow up

Patient says no
No contact with family
Patient contacted prior to discharge to invite for 2 month interview
See Flow chart 4

Family decline initial interview
No Initial interview with family
See Flow chart 4

Interview conducted: Consent sought for approach to follow up interview (FCF2)

These flow charts are intended to show the processes in place to ensure patients are given sufficient information and opportunity to make an informed decision about taking part in this research, and to give them sufficient opportunity to take part in the research. They are be necessity complicated. When following these charts all pathways should be explored to ensure all circumstances are accounted for.
This flow chart shows the process for contacting patients and the families of patients with capacity to provide them with information and to ask if they would agree to a follow-up interview. The process is designed to ensure that patients and family members are given sufficient information and opportunity to make an informed decision about taking part in the research, without burdening them with contacts they have previously declined.