Additional File 1 — Questionnaire Booklet

Question 1
Are you:
- British
- Irish
- Any other white background (specify)
- White & Black Caribbean
- White & Black African
- Any other mixed background (specify)
- Indian
- Pakistani
- Bangladeshi
- Any other Asian background (specify)
- Caribbean
- African
- Any other black background (specify)
- Chinese
- Any other (specify)

Question 2
Does your household own or rent the accommodation?
- Owns outright
- Owns with a mortgage or loan
- Pays part rent and part mortgage
- Rents your accommodation
- Lives rent free

Question 3
What is your marital status?
- Married
- Divorced
- Separated, but still legally married
- Widowed
- Never married
**Question 4**
Has your marital status changed as a direct result of admission and recovery from your intensive care unit experience?

- No, my marital status has not changed
- Yes, my marital status has changed
  - Divorced
  - Re-married
  - Separated but still legally married

**Question 5**
What was your employment status BEFORE the event that led to your intensive care unit admission? Please tick one only

- Full-time employment
- Part-time employment
- Early retirement
- Retired (at statutory age)
- Unemployed/not paid employment
- Long-term sick leave
- Other (specify)

**Question 6**
Were you receiving any of the following financial support PRIOR to your admission to the intensive care unit? Please tick all that apply

- None, I did not apply for financial support
- Any state benefits and/or direct payments from social services
- Care vouchers
- Other (specify)

**Question 7**
Has your employment had to change as a result of the event that led to your intensive care unit admission? Please tick one only

- No, my employment has not changed
- Yes, my employment has changed
  - Had to give up paid employment
  - Gone part-time
– Taken early retirement
– On long-term sick leave
– Currently unemployed/not paid employment
– Other (specify)

**Question 8**
Tick as many boxes as you need to show all the sources of income you had in the 12 months BEFORE your admission to the intensive care unit.

- Earnings, wages, salary, bonuses
- Income from self-employment
- Occupational pensions, state retirement pension
- State benefits such as incapacity benefit, child benefit or tax credits
- Interest from savings or investments
- Rent from property
- Other income
- No source of income during that time

**Question 9**
Tick as many boxes as you need to show all your CURRENT sources of income.

- Earnings, wages, salary, bonuses
- Income from self-employment
- Occupational pensions, state retirement pension
- State benefits such as incapacity benefit, child benefit or tax credits
- Interest from savings or investments
- Rent from property
- Other income
- No source of income during that time

**Question 10**
From all the sources of income you ticked in question 8, what was your average MONTHLY income BEFORE your admission to intensive care unit?

- Nil
- £1 to £319
- £320 to £599
• £600 to £919
• £920 to £1,319
• £1,320 to £1,839
• £1,840 to £2,839
• £2,840 or more

For comparison £1 = 1.7138 USD or 1.2042 EURO [43]

**Question 11**
From all of your sources of income you ticked in question 9, what is your CURRENT average MONTHLY income?

• Nil
• £1 to £319
• £320 to £599
• £600 to £919
• £920 to £1,319
• £1,320 to £1,839
• £1,840 to £2,839
• £2,840 or more

**Question 12**
Are you receiving care?

• Yes
• No Go to question 20

**Question 13**
Which of the following caring activities do you require regularly? Please tick all that apply.

• Personal care (such as dressing, washing, eating)
• Physical care (such as moving, lifting)
• Household duties (such as shopping, cleaning, cooking)
• Health-care (such as administering medications, treatments, medical devices)
**Question 14**
How much time per week do you typically depend upon other people providing care for you?
- 1-19 hours
- 20-34 hours
- 35-49 hours
- More than 50 hours

**Question 15**
Is your carer your next of kin or a close family member?
- Yes
- No, care is provided by social services Go to question 17
- No, I pay for my own care Go to question 17

**Question 16**
Which of the following has your next of kin or family member experienced in order to provide your care?
Please tick all that apply
- They have NOT had to change their job because of their caring responsibilities
- They have been given leave specifically to carry out their caring tasks
- They have had to reduce their working hours because of their caring responsibilities
- They have had to change their job because of their caring responsibilities
- They have had to give up paid employment because of their caring responsibilities

**Question 17**
Which, if any, of the following do you receive as financial support for care? Please tick all that apply
- None, I did not apply for financial support Go to question 19
- Any state benefits and/or direct payments from social services
- Care vouchers
- Other (specify)

**Question 18**
How easy have you or your carer found getting financial support from health and social services?
- I did not apply for any
- Very easy
- Easy
- Difficult
- Very difficult
**Question 19**
Which of the following have you done to provide for your care? Please tick all that apply

- I have done nothing to provide for my care
- Used savings
- Taken out loan/ credit cards
- Re-mortgaged house
- Sold house
- Done extra work
- Applied for money from a charity
- Other (specify)

**Question 20**
Since your discharge from hospital, who, if anyone, have you seen? Please tick all that apply

- I have not seen anyone about my intensive care unit admission
- Community Nurse/Specialist nurse
- Consultant/ Senior Hospital Doctor
- Dietician
- GP
- Hospital nurse/Specialist nurse
- Intensive Care Follow-up clinic/team
- Neuropsychologist (to assess thinking skills)
- Occupational Therapist (OT)
- Physiotherapist
- Psychologist/ counsellor (for emotional support)
- Social Worker
- Speech and language therapist
- Other (specify)
**Question 21**
Since your discharge from hospital, who, if anyone, have you seen specifically about your intensive care admission? Please tick all that apply.

- I have not seen anyone about my intensive care unit admission
- Community Nurse/Specialist nurse
- Consultant/ Senior Hospital Doctor
- Dietician
- GP
- Hospital nurse/Specialist nurse
- Intensive Care Follow-up clinic/team
- Neuropsychologist (to assess thinking skills)
- Occupational Therapist (OT)
- Physiotherapist
- Psychologist/ counsellor (for emotional support)
- Social Worker
- Speech and language therapist
- Other (specify)

**Question 22**
Since your discharge from hospital, who, if anyone, would you have LIKED to have seen specifically about your intensive care admission? Please tick all that apply.

- I have not seen anyone about my intensive care unit admission
- Community Nurse/Specialist nurse
- Consultant/ Senior Hospital Doctor
- Dietician
- GP
- Hospital nurse/Specialist nurse
- Intensive Care Follow-up clinic/team
- Neuropsychologist (to assess thinking skills)
- Occupational Therapist (OT)
- Physiotherapist
- Psychologist/ counsellor (for emotional support)
- Social Worker
- Speech and language therapist
- Other (specify)