



CYCLE RCT #142

Plate #070

Visit #090

Patient ID [] [] [1] [] []
(site #) (patient #)

Coded Patient Initials [] []
F L

Assessor Initials [] []
F L

90 DAY FOLLOW-UP QUESTIONNAIRE (Form RC 4.1 of 13)

Assessment Collection Window:

83 - 120 days post-randomization (ideal = day 90)

SDM/ LAR Can Provide Data For:

Section A = ALL Parts

Section B = ONLY Part 1 "Frailty" (Parts 2, 3, 4 = completed via patient interview or SDM/LAR with patient input)

- 1. Date of randomization [] [] [] [] 2 0 [] [] (dd/mm/yyyy)
- 2. Date of 90 days post-randomization [] [] [] [] 2 0 [] [] (dd/mm/yyyy)
- 3. Date range of assessment [] [] [] [] 2 0 [] [] → [] [] [] [] 2 0 [] [] (dd/mm/yyyy)
(If start date = end date, enter same date in both fields) (start date) (end date)

4. At time of follow-up/ date of assessment, was the patient alive?

Unknown (only choose this if directed by the methods centre; stop here)

No → Record date of death: [] [] [] [] 2 0 [] [] (dd/mm/yyyy)

Before they died, did the patient spend any time in the following locations:

Home/Retirement Home, Assisted Living Facility, Nursing Home, Long Term Care Facility, Chronic Care Facility

No → (Stop here)

Yes → (Complete Section A only; go to page 4.2)

Yes → At the time of follow-up, did the patient spend any time in the following locations since hospital discharge:

Home/Retirement Home, Assisted Living Facility, Nursing Home, Long Term Care Facility, Chronic Care Facility

No → (Complete Section B only; go to page 4.2)

Yes → (Complete Sections A + B; go to page 4.2)

***Section A does not need to be completed if the patient has only spent time in any the following locations since randomization: hospital, inpatient rehabilitation, long term acute care, skilled nursing facility**

****If the patient has spent time in locations not listed above, and you are unsure if section A should be completed, please contact the methods centre for guidance prior to starting the assessment.**



CYCLE RCT #142

Plate #072

Visit #090

Patient ID [] [] 1 [] [] (site #) (patient #)

Coded Patient Initials [] [] F L

Date of Assessment [] [] [] [] 20 [] [] (dd/mm/yyyy)

90 DAY FOLLOW-UP QUESTIONNAIRE (Form RC 4.3 of 13)

SECTION A: UTILIZATION

Please complete this section if patient spent time in any of the following locations since date of randomization: Home/ Retirement Home, Assisted Living Facility, Nursing Home, Long Term Care Facility, Chronic Care Facility

- Reason # not done
1 = Unable to contact patient or SDM/LAR
2 = Patient/ SDM/ LAR does not provide consent (patient/ SDM /LAR contacted)
3 = Patient/ SDM/ LAR refusal (consent acquired)
4 = Assessor perceives patient unable to perform and SDM/ LAR not available
5 = Other (specify)

Reason # not done (if "other", specify)

"Firstly, I would like to ask you some questions about your health care needs and ability to return to your daily activities since being discharged from hospital. If you have information recorded on the patient log provided to you at hospital discharge it would be helpful for you to have this on hand as we go through the questions."

Part 1: Patient Disposition and Living Facilities

1.1 Where are you currently living (if patient not alive at time of follow-up, where were they living previously)?

- Unknown Home (independent) Assisted Living Facility (mostly independent) Inpatient Rehabilitation
Home (w/ home care) Nursing Home/ Long Term Care Facility Acute Care Hospital
Home (w/unpaid caregiver assistance) Chronic Care Facility/ Complex Continuing Care/ Skilled Nursing Facility Other (specify)
Retirement Home (independent) Long Term Acute Care (LTAC)

1.2 Marital status (check ONE box)

- Unknown Single Married or Common law Separated or Divorced Other (specify)

1.3 Since your hospital discharge, have you had any admissions to a long term care facility?

- Unknown No Yes -> How many days? (# days) Unknown

1.4 Since your hospital discharge, have you spent any time in a retirement home?

- Unknown No Yes -> How many days? (# days) Unknown

1.5 Since your hospital discharge, have you spent any time in an assisted living facility?

- Unknown No Yes -> How many days? (# days) Unknown

1.6 Since your hospital discharge, have you spent any time in/ in a chronic care facility/ complex continuing care/ skilled nursing facility?

- Unknown No Yes -> How many days? (# days) Unknown

1.7 Since your hospital discharge, have you spent any time in long term acute care (LTAC)?

- Unknown No Yes -> How many days? (# days) Unknown

1.8 Since your hospital discharge, have you spent any time in an inpatient rehab?

- Unknown No Yes -> How many days? (# days) Unknown

1.9 Since your hospital discharge, have you spent any time in any other locations not listed above (e.g. drug rehab facility)?

- Unknown No Yes (specify)

Part 2: Emergency Room Visits and Hospitalizations

2.1 Since your hospital discharge, have you visited an emergency room for any reason?

- Unknown No Yes -> How many times? (# visits) Unknown

[Interviewer: For each emergency room visit, ask the patient the reason for the visit]

VISIT #1: Unknown Reason:

VISIT #2: Unknown Reason:

VISIT #3: Unknown Reason:



CYCLE RCT #142

Plate #074

Visit #090

Patient ID [] [] [1] [] [] [] (site #) (patient #)

Coded Patient Initials [] [] F L

Date of Assessment [] [] [] [] [2] [0] [] [] (dd/mm/yyyy)

90 DAY FOLLOW-UP QUESTIONNAIRE (Form RC 4.5 of 13)

Part 3: Family Doctor Visits

3.1 Since your hospital discharge, have you been to see your family doctor for any reason?

- Unknown (go to 4.1)
No (go to 4.1)
Yes -> How many visits? (# visits)
Unknown

3.2 Do you feel any of these family doctor visits were because of your initial admission to the ICU 3 months ago

- Unknown
No
Yes -> How many visits? (# visits)
Unknown

Part 4: Specialist Visits

4.1 Since your hospital discharge, have you visited a specialist for any reason?

- Unknown (go to 5.1)
No (go to 5.1)
Yes (complete table below)

[Interviewer: If yes, ask the patient about the type(s) of specialist(s), the number of visits to each, and how many of these visits were because of their admission to ICU]

Table with columns: Specialist, Visited/ Seen (Unknown, No, Yes), Visits (Unknown, #), Visits related to initial ICU admission (Unknown, #), Reimbursed by government and/ or insurance plan (Unknown, No, Yes). Rows include Neurologist, Respiriologist/ Pulmonologist, Cardiologist, Dermatologist, Ear/Nose/Throat Specialist, Gastroenterologist, Psychiatrist (Rehabilitation Doctor), Nephrologist, Psychiatrist, Surgeon, Dentist, and two 'Other' rows.



CYCLE RCT #142

Plate #075

Visit #090

Patient ID [] [] [1] [] [] (site #) (patient #)

Coded Patient Initials [] [] F L

Date of Assessment [] [] [] [] [2] [0] [] [] (dd/mm/yyyy)

90 DAY FOLLOW-UP QUESTIONNAIRE (Form RC 4.6 of 13)

Part 5: Other Healthcare Professionals/ Services

5.1 Since your hospital discharge, have you seen any other healthcare professionals or used any of the following services for any reason?

- Unknown (go to 6.1A)
No (go to 6.1A)
Yes (complete table below)

[Interviewer: If yes, ask the patient about the type(s) of professional(s), the number of visits to each, and how many of these visits were because of their admission to ICU]

Table with columns: Professional, Visited/ Seen (Unknown, No, Yes), Visits (Unknown, #), Visits related to initial ICU admission (Unknown, #), Reimbursed by government and/ or insurance plan (Unknown, No, Yes). Rows include Nurse Practitioner, Visiting Nurse, Private Nurse, Homemaker, Physiotherapist, Occupational Therapist, Speech Language Pathologist, Respiratory Therapist, Dietitian, Social Worker, Psychologist, Chiropractor, Naturopath, Employment Retraining Services, Meals-on-wheels, Transportation Services, and Other.



CYCLE RCT #142

Plate #077

Visit #090

Patient ID 1
(site #) (patient #)

Coded Patient Initials
F L

Date of Assessment 2 0
(dd/mm/yyyy)

90 DAY FOLLOW-UP QUESTIONNAIRE (Form RC 4.7 of 13)

Part 6: Assistance from Others (e.g. spouse, relative, friend, other caregiver)

6.1 Since your hospital discharge, have you required assistance from others to help you with your daily activities?

- Unknown
- No → (go to 7.1)
- Yes

6.2 For how many weeks did you require assistance from others with your daily activities?

- Unknown
- (# weeks)

6.3 For how many hours on average in a typical week did you require this assistance?

- Unknown
- (# hours)

6.4 Was the person who was assisting you working?

- Unknown
- No → (go to 7.1)
- Yes

6.5 Did this person have to take time off work?

- Unknown
- No → (go to 7.1)
- Yes

6.6 How many days did this person have to take off from work?

- Unknown
- (# days)



CYCLE RCT #142

Plate #076

Visit #090

Patient ID [] [] [] 1 [] [] []
(site #) (patient #)

Coded Patient Initials [] []
F L

Date of Assessment [] [] [] [] 2 0 [] []
(dd/mm/yyyy)

90 DAY FOLLOW-UP QUESTIONNAIRE (Form RC 4.8 of 13)

Part 7: Employment Status and Time-off-work from Paid Employment

7.1A How many hours per week are you currently working?

Unknown [] [] (# hours)

7.1B Before you were admitted to the ICU 3 months ago, which of the following best describes your employment status or main activity?

[Interviewer: Read list and tick one box only]

- Unknown (1) Working at a full-time job (>35 hours/week)
- (2) Working at a part-time job (<35 hours/week)
- ▶ **If (1) or (2) go to Q7.2**
- (3) Employed but on temporary sick leave or long-term disability
- (4) Looking for work/between jobs
- (5) Going to school
- (6) Homemaking
- (7) Retired
- (8) Other (specify) _____

—▶ **If (3) to (8) Section A is complete (do not complete 7.2 to 7.4)**

7.2 If you were working full-time/part-time before your admission to the ICU, how many hours/week were you working in a typical week?

Unknown [] [] (# hours)

7.3 Have you returned to work since your ICU admission 3 months ago?

- Unknown No —▶ (Section A is complete)
- Yes —▶ (go to 7.4)

7.4 What was the date of your first day back at work; number of weeks after hospital discharge patient returned to work?

Unknown [] [] [] [] 2 0 [] [] (dd/mm/yyyy)

OR

[] [] (# weeks)

END SECTION A

****Stop here if the patient died during hospital stay relative to the index admission****

Continue to Section B if patient is alive at the time of follow-up



CYCLE RCT #142

Plate #078

Visit #090

Patient ID [] [] 1 [] [] (site #) (patient #)

Coded Patient Initials [] [] F L

Date of Assessment [] [] [] [] 2 0 [] [] (dd/mm/yyyy)

90 DAY FOLLOW-UP QUESTIONNAIRE (Form RC 4.9 of 13)

SECTION B: PATIENT REPORTED OUTCOMES

Please complete this section if patient is alive at the time of follow-up

*Section must be completed by patient or by SDM/LAR with patient input, with the exception that "Clinical Frailty Scale" can be completed by SDM/LAR only.

Reason # not done

- 1. (Intentionally omitted) 2. (Intentionally omitted) 3. (Intentionally omitted) 4. (Intentionally omitted) 5. Patient or Proxy refusal 6. Assessment missed 7. Cognitive issue - patient too sedated/agitated 8. Cognitive issue - patient unable to follow commands 9. (Intentionally omitted) 10. (Intentionally omitted) 11. Other assessment prioritized 12. Other (specify)

Part 1: Clinical Frailty Scale

[Interviewer: Ask the patient questions as necessary to discern their level of frailty based on the scale below. The following are some questions that may help clarify the patient's health status, level of activity, and functional status]

2.1 Do you need help with the following activities?

- Bathing (if so, how much help?) Dressing (if so, how much help?) Transportation Light housekeeping Heavy housework Finances Outside activities Taking medications Meal preparation

2.2 Do you experience any disease symptoms throughout your day (e.g. SOB, pain, headache, etc.)?

- No Yes do these symptoms limit your activities or cause you to feel slowed up and/or tired throughout the day? No Yes

2.3 How are you managing with the stairs?

2.4 How often do you exercise?

- Regularly Seasonally or occasionally Not regularly beyond routine walking

2.4 Do you feel fitter than most people your age?

- No Yes

[Interviewer: please select the highest score from the descriptions below from 1 to 9. If the patient has characteristics from higher descriptors, then please report the highest score.]



CYCLE RCT #142

Plate #079

Visit #090

Patient ID (site #) [] [] [] 1 [] [] [] (patient #)

Coded Patient Initials [] [] [] [] F L

Date of Assessment [] [] [] [] [] [] 2 0 [] [] (dd/mm/yyyy)

90 DAY FOLLOW-UP QUESTIONNAIRE (Form RC 4.10 of 13)

*Section can be completed by SDM/LAR only, patient or SDM/LAR with patient input.

Considering the patient's current status, please select the highest score from the descriptions below from 1 to 9. If the patient has characteristics from higher descriptors, then please report the highest score.

[] [] Reason # not done (specify) _____



1. VERY FIT: People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.



2. WELL: People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally



3. MANAGING WELL: People whose medical problems are well controlled, but are not regularly active beyond routine walking.

SCORE

[]



4. VULNERABLE: While not dependent on others for daily help, often symptoms limit activities. A common complaint is being "slowed up", and/or being tired during the day.



5. MILDLY FRAIL: These people often have more evident slowing, and need help in high order IADLS (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.



6. MODERATELY FRAIL: People who need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.



7. SEVERELY FRAIL: Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).



8. VERY SEVERELY FRAIL: Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness



9. TERMINALLY ILL: Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.

Scoring frailty in people with dementia: The degree of frailty corresponds to the degree of dementia.

Common symptoms in mild dementia include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In moderate dementia, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In severe dementia, they cannot do personal care without help.

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As of March 31, 2023 (Live Version 3); Replaces November 30, 2021 (Live Version 2)



CYCLE RCT #142

Plate #080

Visit #090

Patient ID (site #) 1 (patient #)

Coded Patient Initials F L

Date of Assessment (dd/mm/yyyy) 20

90 DAY FOLLOW-UP QUESTIONNAIRE (Form RC 4.11 of 13)

*Section must only be completed by patient or SDM/LAR with patient input.

Part 2: EQ-5D

1. "I will read several statements pertaining to a particular topic to you and I would like you to tell me which best describe your health today." "The next section of this questionnaire focuses on quality of life."

[Interviewer: Read each statement for each category and tick the corresponding box to the patient's response]

2. "We would like to know how good or bad your health is today. Picture a scale numbered from 0 to 100. 100 means the best health you can imagine. 0 means the worst health you can imagine. Where on this scale would you place your health today?"

[Interviewer: Record the number between 0-100 in the provided box]

1. EQ-5D: Descriptive System: Today's Perception

Reason # not done (specify)

2. EQ-5D: Visual Analogue Scale: Today's Perception

Reason # not done (specify)

MOBILITY

- I have no problems in walking about
I have slight problems in walking about
I have moderate problems in walking about
I have severe problems in walking about
I am unable to walk about

SELF-CARE

- I have no problems washing or dressing myself
I have slight problems washing or dressing myself
I have moderate problems washing or dressing myself
I have severe problems washing or dressing myself
I am unable to wash or dress myself

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

- I have no problems doing my usual activities
I have slight problems doing my usual activities
I have moderate problems doing my usual activities
I have severe problems doing my usual activities
I am unable to do my usual activities

PAIN / DISCOMFORT

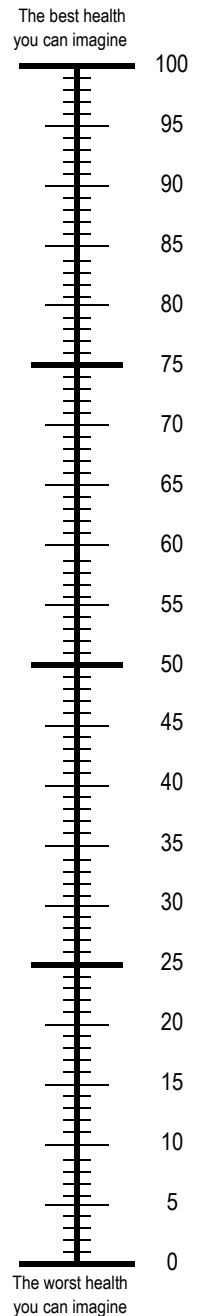
- I have no pain or discomfort
I have slight pain or discomfort
I have moderate pain or discomfort
I have severe pain or discomfort
I have extreme pain or discomfort

ANXIETY / DEPRESSION

- I am not anxious or depressed
I am slightly anxious or depressed
I am moderately anxious or depressed
I am severely anxious or depressed
I am extremely anxious or depressed

YOUR HEALTH SCORE TODAY

Health score input box





CYCLE RCT #142

Plate #081

Visit #090

Patient ID [] [] 1 [] [] (site #) (patient #)

Coded Patient Initials [] [] F L

Date of Assessment [] [] [] [] 2 0 [] [] (dd/mm/yyyy)

90 DAY FOLLOW-UP QUESTIONNAIRE (Form RC 4.12 of 13)

*Section must only be completed by patient or SDM/LAR with patient input.

Part 3: Hospital Anxiety and Depression Scale

[] Reason # not done (specify)

"I will now read some statements and replies to you that relate to anxiety and depression. For each statement, please let me know which reply is the closest to how you have been feeling in the past week."

[Interviewer: Tick the box beside the patient's response for each question. See the scoring instructions below. The patient will receive a separate score for each Depression and Anxiety]

Hospital Anxiety (A) and Depression (D) Scale (HADS)

Table with 14 rows of statements and 12 columns for D and A scores (0, 1, 2, 3). Includes statements like 'I feel tense or wound up', 'I still enjoy things I used to enjoy', etc.

SCORING

SUM

Scoring table with rows for DEPRESSION TOTAL and ANXIETY TOTAL, and columns for calculations: [] x 0 = [] [], [] x 1 = [] [], [] x 2 = [] [], [] x 3 = [] [], and a final SUM column.

Scoring Instructions: Add up the number of checkmarks in each vertical column and write the total on the blank line at the bottom of that column. Multiply each column's total by the corresponding score for that column (0, 1, 2, or 3) and write this in the blank box. Add up the total of the boxes horizontally across each row to determine the separate total scores for both depression and anxiety

(0-7 = Normal ; 8-10 = Borderline Abnormal ; 11-21 = Abnormal)



CYCLE RCT #142

Plate #082

Visit #090

Patient ID [] [] 1 [] [] (site #) (patient #)

Coded Patient Initials [] [] F L

Date of Assessment [] [] [] [] 2 0 [] [] (dd/mm/yyyy)

90 DAY FOLLOW-UP QUESTIONNAIRE (Form RC 4.13 of 13)

*Section must only be completed by patient or SDM/LAR with patient input.

Part 4: Patient-Reported Functional Scale - ICU

[] [] Reason # not done (specify) _____

"I'm going to ask you about how well you think you can do 6 activities today, compared to your ability to do them before your ICU admission. Picture a scale from 0 to 10. 10 means you can do the activity as well as you could before your ICU admission. 0 means you are unable to do this activity now."

[Interviewer: Read the activities from 1-6 and record patient's score in the provided box. If the patient reports the activity is not relevant to them, please state, "If you are not doing this now, do you imagine you would have any difficulty?"]

Unable to perform activity 0 1 2 3 4 5 6 7 8 9 10 Able to perform activity at same level as before ICU admission

Table with 2 columns: ACTIVITY and SCORE. Rows include activities like 'Rolling in bed', 'Moving from lying in the bed to sitting at the edge of the bed', etc., and a final row for 'FINAL SCORE (sum total / 6)'.

END SECTION B