

Persistent critical illness characterised by Australian and New Zealand ICU clinicians

Theodore J Iwashyna, Carol L Hodgson,
David Pilcher, Michael Bailey and Rinaldo Bellomo

Chronic critical illness has become an increasingly recognised problem with a growing population of patients.¹⁻³ Several types of chronic critical illness may be distinguished, including:

- patients whose major problem is persistent respiratory failure requiring prolonged mechanical ventilation (PMV),^{4,5} and
- patients at high risk for being eligible for use of a long-term acute care facility within the United States health care system.^{1,6}

These definitions tend to focus on the ultimate outcome of care, which is unknowable to clinicians during the act of caring for patients; furthermore, these definitions were often developed with little input from practising intensive care unit clinicians, so their relevance to ICU clinical practice is unknown.

The concept of persistent critical illness (PerCI) may be of use to ICU clinicians to describe a distinct group of patients within the ICU, as we have proposed elsewhere in the Journal.⁷ Specifically, it may be useful to identify the characteristics of patients whose reason for being in the ICU is now more related to their ongoing critical illness than their original reason for admission to the ICU. It may also be useful to determine the perceived relationship between PerCI and simply prolonged ICU length of stay.

The aim of our study was to determine, via survey, the perspectives of Australian and New Zealand clinicians involved in the Australian and New Zealand Intensive Care Society (ANZICS) Clinical Trials Group (CTG) regarding patients with PerCI.

Methods

Survey development

The anonymous survey was developed using an iterative process.⁸ First, we identified and refined the subject domains, alternative specific question items, and their response structures within our multidisciplinary author group. A prototype survey was coded in SurveyMonkey. This prototype underwent “cognitive interviewing” with six consultant intensivists, in which the intensivists talked aloud about their thought processes in answering each question, to ensure consistent and easy comprehension.⁹ The survey items were refined repeatedly until consistent responses

ABSTRACT

Objective: To identify the characteristics of patients with “persistent critical illness” (PerCI), as perceived by Australian and New Zealand intensive care unit clinicians. Patients with PerCI were defined as those whose reason for being in the ICU was now more related to their ongoing critical illness than their original reason for admission to the ICU.

Design and participants: Using a web-based survey, we recruited clinicians affiliated with the Australian and New Zealand Intensive Care Society (ANZICS) Clinical Trials Group (CTG) who cared for adults. Clinicians included doctors, nurses, physiotherapists, dietitians, research managers and others. We used the ANZICS-CTG mailing list to email a single request for anonymous participation.

Results: A total of 101 eligible clinicians responded to our survey. PerCI was believed to develop after a median of 10 days (IQR, 7–14 days), and to be somewhat uncommon (occurring in 10% of all ICU patients [IQR, 5%–15%], and in 50% of all patients with a prolonged ICU length of stay [IQR, 20%–60%]). Ninety per cent of respondents thought that patients with PerCI required ongoing invasive mechanical ventilation, and the most common problems were thought to be respiratory insufficiency (68%), delirium (59%) and acquired neuromuscular disease (54%). Ten per cent of patients with PerCI were expected to be alive and well and at home 6 months after ICU discharge, with another 15% alive and at home but requiring significant help. The remainder were expected to die within 6 months or to need institutional care.

Conclusion: Patients with PerCI appear to be an identifiable group of ICU patients, with definable characteristics, substantial stress associated with their care, and poor perceived long-term outcomes.

Crit Care Resusc 2015; 17: 153–158

were obtained on each item. A near-final survey was pilot-tested with 12 experienced ICU research staff to confirm feasibility, time-burden and clarity.

The final survey included 27 questions (Appendix 1). Three questions included multicategory lists (of six, 14 and 16 items) in which the respondents could designate as

Table 1. Summary of recommendations for improvement

Domain of recommendations	<i>n</i>	%
Multidisciplinary coordination	38	20%
Physiotherapy	30	16%
Improve communication with family	18	10%
Nutrition	14	7%
Changes to end-of-life care	13	7%
Setting of limits by care team	9	5%
Prevention of specific complications	8	4%
Treatment or management of delirium	7	4%
Identification and recognition	7	4%
Other or not otherwise categorised	6	3%
Specific care practices	38	20%

many responses as they wished. In order to minimise order-of-presentation bias in these lists, their order was randomly reshuffled for each respondent. In order to inform the category choice for conditions that might have a prolonged intrinsic recovery time (Question 11), data from the ANZICS Centre for Outcome and Resource Evaluation (CORE) Adult Patient Database (APD) were reviewed. The APD is a patient-level database, maintained by CORE, that includes > 1.5 million ICU admissions and > 90% of all ICU admissions in Australia and New Zealand.¹⁰ We excluded diagnoses for which < 10% of patients had ICU lengths of stay > 5 days, and for which there were fewer than 5000 admissions in the APD for 2000–2014.

The survey and all invitation documents were reviewed and approved by the Alfred Hospital Ethics Committee (Project 124/15).

Recruitment and inclusion criteria

Participants were recruited from a general email to the ANZICS CTG from its executive office. Because of CTG policy, no individualised or follow-up recruitment emails could be sent. No specific financial inducement was offered. The recruitment email included basic information about the study and a link to the SurveyMonkey website. A full explanatory statement was attached to the email, documenting relevant ethical and privacy protection practices. The survey was sent on 7 April 2015 with a deadline to respond by 24 April 2015, and the last included responses were received on 11 May 2015. The recruitment documents can be seen in Appendix 1 (online at cicm.org.au/Resources/Publications/Journal).

The email invited responses from anyone who was “a member of ... ANZICS CTG and/or ... CICM.” Our analyses excluded five people who indicated that they did not care for adult patients.

Table 2. Self-reported demographics of respondents*

Demographic	Data	<i>n</i>
Role, % of respondents		
ICU consultant	70%	59
Research coordinator	12%	10
Nurse	17%	14
Project manager	1%	1
Dietitian	13%	11
Physiotherapist	5%	4
Other	2%	2
Age, years		
≤ 29	1%	1
30–39	29%	21
40–49	31%	22
50–59	32%	23
60–69	7%	5
≥ 70	0	0
Mean years since training completing (SD)	15.5 (9.1)	72
Mean ICU size, beds (SD)	24.5 (13.4)	72
Hospital type, %		
Private	6%	4
Public	94%	67
CICM trainees in the ICU		
Yes	97%	69
No	3%	2
Practice location, %		
New Zealand	13%	9
Australian Capital Territory (Australia)	3%	2
New South Wales (Australia)	15%	11
Northern Territory (Australia)	3%	2
Queensland (Australia)	18%	13
South Australia (Australia)	7%	5
Tasmania (Australia)	0	0
Victoria (Australia)	39%	28
Western Australia (Australia)	3%	2

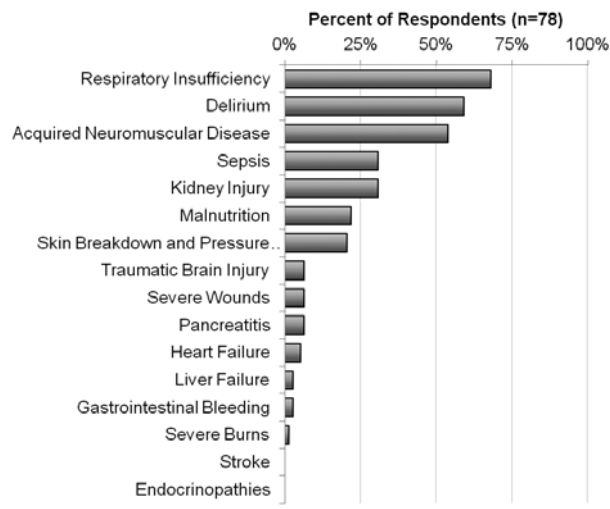
ICU = intensive care unit. CICM = College of Intensive Care Medicine.

* Other than professional role, these items came last in the questionnaire, so individuals who stopped early were missing data.

Statistical and qualitative analyses

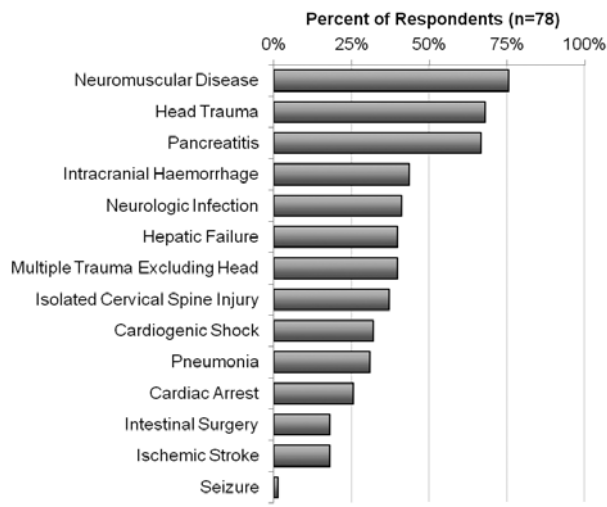
We show normally distributed variables as means and SDs, and non-normally distributed variables as medians and interquartile ranges (IQRs). Percentages reported are the fractions of all respondents who answered each survey item; that is, we used casewise deletion of missing data, separately for each reported item. We used χ^2 tests to compare whether or not individual items were differentially identified by medical staff versus other clinicians (eg, was

Figure 1. Typical problems of patients with persistent critical illness*



* Responses to the question (of those who provided at least one answer): "In your opinion, what are the 3 most common ongoing problems of a prototypical patient with persistent critical illness?".

Figure 2. Diseases with long intrinsic recovery times*



* Responses to the question (of those who provided at least one answer): "Some diseases simply take a long time to recover in the ICU because of their own unique pathophysiology. In your opinion, even without severe complications, which if any of the following conditions often require long stays in the ICU in themselves without persistent critical illness?".

invasive mechanical ventilation a prototypical feature of PerCI?), and we used Wilcoxon rank-sum tests to examine differences in percentages of patients likely to have each outcome. We analysed our results using Stata, version 13.1

(StataCorp) and set P at <0.05 for statistical significance. We made no adjustments for multiple comparisons.

Free-text answers were requested to the question "What do you think are the three most important things that could be done to improve care of patients with persistent critical illness?" Two reviewers independently examined all the recommendations, separately developed proposed coding categories, and then discussed them to develop consensus coding categories, shown in Table 1. They independently coded all the recommendations into the consensus categories, then resolved differences with discussion.

Results

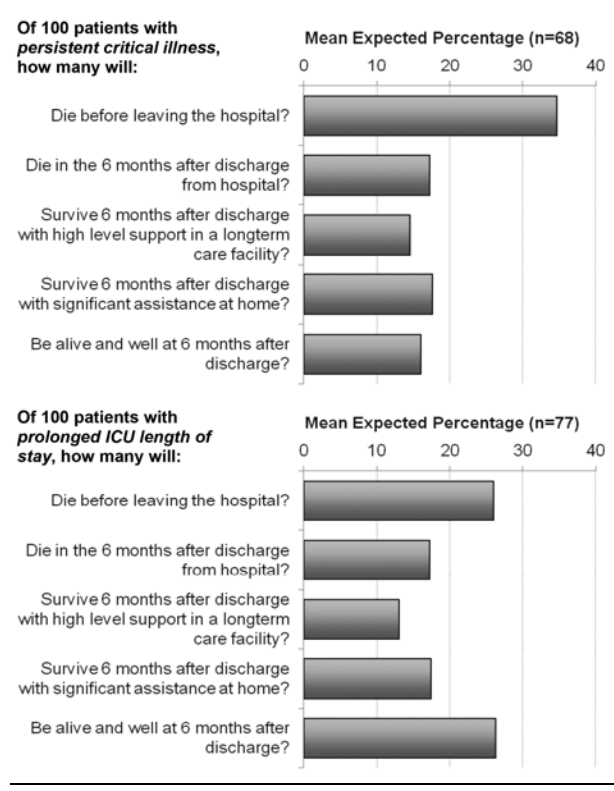
There were 101 clinicians working in adult ICUs who responded to the survey, of whom 58% self-identified as ICU consultants, with the balance working in other ICU professions. Demographics of the respondents are shown in Table 2, and question-specific response rates are shown in Appendix 2 (online at cicm.org.au/Resources/Publications/Journal).

The defining feature of patients with PerCI was invasive mechanical ventilation—90% identified it as one of the most common ongoing needs of such patients, with 80% identifying tracheostomies as common in the prototypical persistently critically ill. There were disagreements about other procedures: 63% of respondents thought that dialysis was a prototypical ongoing need, and 37% selected continuous infusions of vasoactive medications. In contrast, most respondents did not think that parenteral nutrition (17%) or ventricular-assist devices were prototypical (5%). Medical staff were less likely to identify continuous infusions of vasoactive medications than non-medical staff (28% v 53%; $P=0.025$); otherwise, the patterns were similar within the limits of the sample size.

Three clinical problems dominated responses about the prototypical patient: respiratory insufficiency (68%), delirium (59%) and acquired neuromuscular disease (54%). Overall, 64% of doctors, but only 36% of non-medical staff, identified acquired neuromuscular disease as a prototypical problem ($P=0.016$; all other differences, $P>0.05$). As shown in Figure 1, all other problems were felt to be prototypical by fewer than one-third of respondents.

Australian and New Zealand ICU clinicians reported that the onset of PerCI was typically a median of 10 days after ICU admission (IQR, 7–14 days) and that it was uncommon, with a median of only 10% of all ICU patients (IQR, 5%–15% of patients) meeting their definition. Respondents reported that a median of 50% of patients (IQR, 20%–60% of patients) who had a prolonged ICU length of stay did so because they developed PerCI. There was some agreement about conditions that should be excluded from PerCI

Figure 3. Expected outcomes of persistent critical illness (upper panel) and prolonged ICU length of stay (lower panel)*

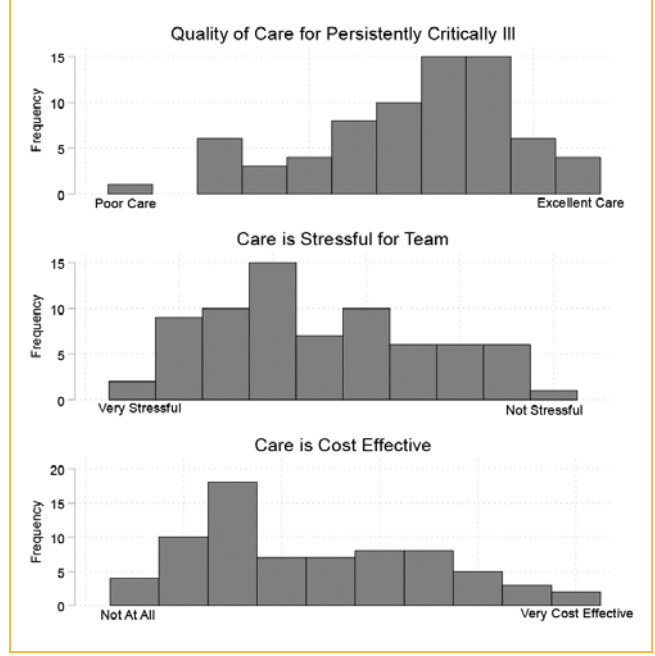


ICU = intensive care unit. * Horizontal axis: mean (not median) percentage of responders who expected to have that outcome; questionnaire logic required that individual answers add to 100 for each respondent.

because of a long intrinsic recovery time. These included neuromuscular disease (76%), head trauma (68%) and pancreatitis (67%). For other conditions, there was greater disagreement, as shown in Figure 2. Medical staff and non-medical staff disagreed about neuromuscular disease (84% v 61%; $P=0.02$), pancreatitis (76% v 50%; $P=0.02$), and isolated cervical spine injury (46% v 21%; $P=0.03$), but not statistically significantly about other conditions ($P>0.05$, with no adjustment made for multiple comparisons).

Outcomes of PerCI were felt to be poor (Figure 3). A median of 30% of patients were expected to die before leaving the hospital (IQR, 20%–50%; mean, 34%); a median of 10% (mean, 16%) were expected to be alive and well at home at 6 months, and a median of an additional 15% (mean, 18%) home but requiring significant assistance at the same time. Only 9% of clinicians thought that most patients with PerCI would be at home (with or without significant assistance) at 6 months. There were no statistically significant differences between the

Figure 4. Self-reported perceptions of quality of care for the persistently critically ill



opinions of medical staff and non-medical staff on these matters. There was disagreement about the quality of care provided to patients with PerCI, as shown in Figure 4. As further shown in Figure 4, many respondents reported that the care of the persistently critically ill was stressful for their teams, and few thought that care of the persistently critically ill was cost-effective as currently provided. There were no systematic differences between medical staff and other clinicians in their responses to these questions.

Respondents provided a total of 188 recommendations for improving care of the persistently critically ill. Table 1 shows the categories of responses after coding. The most common recommendations were to improve multidisciplinary coordination and planning (20%), improve access to physiotherapy (16%), improve communication with families (10%) and the nutrition provided to patients (8%). Specific recommendations included identifying a “champion” for each patient to ensure coordination of their care; improving patients’ access to light and the outdoors, even while still intubated; and improving resuscitation and other general ICU care practices.

Discussion

ICU clinicians in Australia and New Zealand defined a small, but important, minority of their patients as having PerCI. This population was marked by continued ventilator

dependence and a variety of ongoing problems (of which respiratory failure was only one, and was not universally experienced). Acquired neuromuscular disease and delirium were perceived to be common in these patients. Their outcomes, even at 6 months, were thought to be poor. ICU clinicians in Australia and New Zealand often feared that they provided less-than-excellent care to such patients, found the care stressful for their teams, and rarely believed it to be cost-effective. Medical staff and other clinicians reported broadly similar patterns regarding these issues.

Relationship to past studies

There are few studies in the literature which are directly comparable with ours. Several groups have published descriptions of patients undergoing PMV,¹¹⁻¹³ including tools for predicting risk of death,¹⁴ showing the poor outcomes of patients on PMV,^{5,15} and showing the poor communication and unrealistic expectations of their clinician and family caregivers.⁴

The incidence of PMV has been described in several countries or jurisdictions, but those studies were of patients with different characteristics from the patients in our study.¹⁶⁻¹⁸ Ely and colleagues noted that many critical care providers feared that PMV would be a consequence of delirium, concordant with our respondents also noting a high rate of delirium among the persistently critically ill.¹⁹ We were not aware of any studies which engaged a large group of clinicians to characterise the patients we classify as persistently critically ill. We believe that the question of whether persistent respiratory problems (those highlighted by the label "PMV") are the major drivers of PerCI, or are instead simply a manifestation of the underlying inability to sustain homeostasis without intensive care support,⁷ is an unresolved empirical question.

Possible targets for improved care

The ICU clinicians we asked had numerous suggestions for improving the care of PerCI patients. Three ideas stood out. First, there was widespread belief that the persistently critically ill would benefit from greater coordination and shared planning between team members, week-to-week, and across professions. Second, there was a perceived need to improve the quality of communication with family members, both in educating them about the likely outcomes of PerCI and in incorporating their voices and expertise on patients' values into care decisions. Third, there were concerns that the lack of adequate early physical therapy, nutrition and treatment for delirium were contributing to patients' PerCI. The high levels of response to these optional free-text answers suggested that there may be substantial interest in clinical trials to improve the care of these patients.

Before any of these interventions can be tested, two steps need to be taken:

- development of a valid, reproducible case definition of PerCI, allowing enrolment in prospective studies and potentially in randomised clinical trials
- confirmation that the clinical intuitions reported here do, in fact, reflect the clinical and epidemiological reality of meaningful numbers of patients.

Strengths and limitations

Our study has several limitations. We conducted the survey in a convenience sample of practising ICU clinicians from Australia and New Zealand. Recruiting these participants from the CTG mailing list ensured a higher degree of interest in and commitment to research, but may have limited the generalisability of these data to non-CTG clinicians or those in other geographic regions. Most importantly, we report one set of perceptions about these patients and their perceived outcomes. Our survey should inform the development of an operational case definition for rigorous clinical epidemiological investigations into the natural history and outcomes of PerCI. Our survey can contribute to the development of that case definition, but it cannot replace that epidemiological investigation. Given the poor match found in the US between doctors' expectations of outcomes for patients with PMV, and their actual outcomes,⁴ such epidemiological investigation is warranted before using these data to prognosticate or inform direct patient care and counselling. A critical next step is to begin defining the mechanisms leading to PerCI, and the possible interventions to prevent its onset or to salvage the persistently critically ill. Our study did not query clinicians about their views on specific potentially modifiable care practices (such as the use of neuromuscular blockade, sedative agents or steroids) that some have implicated in adverse ICU outcomes; this should be included in future work.

Nonetheless, our survey is, to the best of our knowledge, the first large-scale survey of clinicians about any type of chronic critical illness. We believe it is also the first to attempt to elicit clinicians' insights early in the course of the investigation of the concept of PerCI. Our results show areas of broad consensus and areas in which targeted additional research is needed. They also yielded a high degree of enthusiasm and a range of potential interventions on ways to improve the care of these patients.

Conclusion

The population of patients with PerCI appears to be a recognisable clinical entity to Australian and New Zealand ICU clinicians. This condition is not uncommon, is stressful to ICU clinicians, and treatment is thought to be cost-

ineffective. There are multiple interventions which clinicians believe may improve the care of these patients. Rigorous clinical investigation into the natural history of these patients, the extent to which they can be identified early, and the mutability of their fate is urgently needed.

Acknowledgements

We thank the members of the ANZICS CTG community for their time given to the survey development, validation and responses. This work does not necessarily represent the views of the US Government or the Department of Veterans Affairs.

Competing interests

None declared.

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**Appendix 1. This appendix was part of the submitted manuscript and has been peer reviewed.
It is posted as supplied by the authors**

From: **Donna Goldsmith**
To: [xx]
Cc: Carol Hodgson
Subject: Chronic Critical Illness Survey
April 7, 2015 at 1:25 pm

Dear Colleagues

We are requesting your assistance to complete a survey on patients with chronic critical illness-that is, those patients who "get stuck" in the ICU. There are several possible definitions already in the literature, but none has been developed in the ANZ context. In this study, we will ask your views on two different concepts: (1) Prolonged ICU Length of Stay; and (2) Persistent Critical Illness. The survey results will be used to guide case definitions, additional empirical work and potential interventions to improve the care of the chronically critically ill.

Your participation is voluntary and all responses are anonymous. Individual responses will not be identifiable, no identifying information will be recorded on the survey and the Transmission Control Protocol/Internet Protocol (IP) address tracking has been deactivated. The survey should take 10 minutes or less to complete. Please read the explanatory statement, at the beginning of the survey, prior to providing your responses. Completing the survey will be regarded as evidence of your consent to participate. The survey link is:

https://www.surveymonkey.com/s/cci_2015

Please note that this survey is not endorsed by the ANZICS CTG/CICM. Should you have any questions regarding the survey, please feel free to contact Theodore Iwashyna or Carol Hodgson via the CC'd email address above. This survey will close at 11:59 p.m. on Friday, 24 April 2015.

Kind regards,

Donna

Donna Goldsmith
Executive Officer

Australian and New Zealand Intensive Care Society (ANZICS)
Clinical Trials Group (CTG)
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Carlton VIC 3053

Explanatory Statement

Full Project Title:	<i>Australian and New Zealand Perspectives on Chronic Critical Illness</i>
Alfred Hospital Human Research Ethics Committee Number:	124/15
Project Co-ordinating Centre:	<i>Australian and New Zealand Intensive Care Research Centre (ANZIC-RC)</i>
Principal Investigator:	<i>Carol Hodgson</i>
Co-Investigator(s):	<i>Theodore J Iwashyna, Rinaldo Bellomo, David Pilcher, Michael Bailey</i>
Project Co-ordinator:	<i>Theodore J Iwashyna</i>

Why have you been invited to take part?

You have been invited to participate in this study because you are a member of Australian and New Zealand Intensive Care Society Clinical Trials Group (ANZICS CTG) and / or College of Intensive Care Medicine (CICM). We want to understand the views of Australian and New Zealand ICU clinicians regarding patients with enduring critical illness—that is, those patients who “get stuck” in the ICU. There are several possible definitions already in the literature, but none has been developed in the ANZ context.

What does participation in this study involve?

After reading this statement if you wish to take part in the survey please follow the link provided in the email and complete the survey. This study involves answering 30 questions. The survey should take 10 -15 minutes to complete.

What are the possible benefits?

There are no monetary benefits for taking part in this study.

What are the possible risks or inconveniences?

There is no known risk of physical or psychological stress from taking part in this study. Your participation in the study is anonymous; investigators have disabled the Transmission Control Protocol/Internet Protocol (IP) address recording on Survey Monkey to ensure your identification is impossible. The survey does not gather any sensitive information, identifiable information and the study will not impact on any care you provide or other studies.

Do you have to take part in this study?

It is emphasised that you are not required to participate in this study. If you complete the survey your consent will be implied. Your decision on whether or not to participate will not affect your current or future relations with ANZICS CTG, CICM, Monash University or the ANZIC-RC.

Can you withdraw from the study?

Once you have completed and submitted the survey there is no way to withdraw from the study or alter your responses because the responses are kept anonymously. During the survey you can withdraw from the study at any time. However, you cannot withdraw any responses you have given at the point of exit. If you wish to erase your responses before exiting the survey, you will need to backtrack through the survey and delete your response to each completed question.

Confidentiality

Survey Monkey is hosted by a web survey company located in the USA. Survey Monkey will record and store all responses to the survey in the USA. As a result, Survey Monkey is subject to U.S. laws, in particular, to the U.S. Patriot Act that allows authorities access to the records of internet service providers. By not tracking IP addresses, participants will not be identifiable in USA or by the investigators. No personal information or IP address will be recorded in the survey.

Approved

This project has been approved by Alfred Hospital Human Research Ethics Committee on 30 March 2015 as Project Number 124/15.

Feedback procedure

Upon the completion of the study a journal article will be produced and made available via the ANZICS CTG and/ CICM for participants to view.

If you want any further information concerning this project you can contact Theodore Iwashyna, project co-ordinator on theodore.iwashyna@monash.edu or 0409 859 976. Alternatively you can contact the Principle investigator Carol Hodgson at carol.hodgson@monash.edu.

Should you have any complaint concerning the manner in which this research project [124-15](#) is conducted, please do not hesitate to contact Alfred Hospital Human Research Ethics Committee at the following address:

Email: research@alfred.org.au

Address: The Office of Ethics and Research Governance
The Alfred, PO Box 315
Prahran VIC 3181

Telephone: 03 9076 3619

You have been invited to participate in this study because you are a member of Australian and New Zealand Intensive Care Society Clinical Trials Group (ANZICS CTG) and / or College of Intensive Care Medicine (CICM). We want to understand the views of Australian and New Zealand ICU clinicians regarding patients with enduring critical illness—that is, those patients who “get stuck” in the ICU. There are several possible definitions already in the literature, but none has been developed in the ANZ context.

In this study, we will ask your views on two different concepts:

- (1) Prolonged ICU Length of Stay
- (2) Persistent Critical Illness

This survey is being conducted using a platform from Survey Monkey. Survey Monkey is hosted by a web survey company located in the USA. Survey Monkey will record and store all responses to the survey in the USA. As a result, Survey Monkey is subject to U.S. laws, in particular, to the U.S. Patriot Act that allows authorities access to the records of internet service providers. No personal information or IP address will be recorded in the survey. By not tracking IP addresses, participants will not be identifiable in USA or by the investigators.

This project has been approved by Alfred Hospital Human Research Ethics Committee on 30 March 2015 as Project Number 124/15.

*** 1. This survey focuses on adult patients. Do you care for adult patients in the main ICU where you work?**

- Yes
- No

2. Are you a

- ICU Consultant
- Research Coordinator
- Nurse
- Project Manager

Other (please specify)

Prolonged ICU Length of Stay

3. In your opinion, after how many days do you think a patient should be considered as having prolonged ICU length of stay?

Days: [enter number only]

4. What percentage of your patients do you think have a prolonged ICU stay by your definition?

Percentage: [enter number only]

5. Of 100 patients with prolonged ICU length of stay, how many will: (These are mutually exclusive categories)

Die before leaving the hospital?

Die in the 6 months after discharge from hospital?

Survive 6 months after discharge with high level support in a longterm care facility?

Survive 6 months after discharge with significant assistance at home?

Be alive and well at 6 months after discharge?

Prolonged ICU Length of Stay

6. How good do you believe your ICU is at caring for patients with prolonged ICU length of stay?

Poor care

Excellent care

7. How stressful does your ICU team find caring for patients with prolonged ICU length of stay?

Not at all stressful

Severely stressful

8. How cost effective do you think it is to care for patients with prolonged ICU length of stay as you do now?

Not at all cost effective

Very cost effective

9. How often are there delays in ICU admission because beds are already full with patients with prolonged ICU length of stay?

Never

A few times per year

Several times per year

Every 2-3 months

Once per month

Every other week

Weekly

Several times per week

Nearly every day

N/A as I do not make admitting decisions

Persistent Critical Illness

10. A patient with persistent critical illness is defined as a patient whose reason for being in the ICU is NOW more related to their ongoing critical illness than their original reason for admission to the ICU.

Thinking of this different patient population, if a patient is going to develop persistent critical illness, in your opinion, how many days does it typically take to develop persistent critical illness?

Days: [enter number only]

11. However, some diseases simply take a long time to recover in the ICU because of their own unique pathophysiology.

In your opinion, even without severe complications, which if any of the following conditions often require long stays in the ICU in themselves without persistent critical illness?

Consider a "long stay" as longer than your answer to the previous question.

Cardiogenic shock

Ischemic Stroke

Cardiac arrest

Neurologic infection

Pneumonia

Neuromuscular disease

Hepatic failure

Seizure

Pancreatitis

Head trauma

Intestinal Surgery

Multiple trauma excluding head

Intracranial haemorrhage

Isolated cervical spine injury

Other (please specify)

Persistent Critical Illness

12. Think of a prototypical patient with persistent critical illness.

In your opinion, which are the most common ongoing needs of a patient with persistent critical illness?

(The options are presented in a random order to minimise bias)

- | | |
|--|---|
| <input type="checkbox"/> Ventricular assist devices | <input type="checkbox"/> Tracheostomy |
| <input type="checkbox"/> Continuous infusions of vasoactive medication | <input type="checkbox"/> Parenteral (intravenous) nutrition |
| <input type="checkbox"/> Dialysis | <input type="checkbox"/> Invasive mechanical ventilation |

Other (please specify)

13. In your opinion, what are the 3 most common ongoing problems of a prototypical patient with persistent critical illness?

(The options are presented in a random order to minimise bias)

- | | |
|--|---|
| <input type="checkbox"/> Sepsis | <input type="checkbox"/> Acquired neuromuscular disease |
| <input type="checkbox"/> Kidney Injury | <input type="checkbox"/> Severe burns |
| <input type="checkbox"/> Traumatic brain injury | <input type="checkbox"/> Pancreatitis |
| <input type="checkbox"/> Endocrinopathies | <input type="checkbox"/> Skin breakdown and pressure injury |
| <input type="checkbox"/> Stroke | <input type="checkbox"/> Delirium |
| <input type="checkbox"/> Liver failure | <input type="checkbox"/> Heart failure |
| <input type="checkbox"/> Severe wounds | <input type="checkbox"/> Respiratory insufficiency |
| <input type="checkbox"/> Gastrointestinal bleeding | <input type="checkbox"/> Malnutrition |

Other (please specify)

14. In your opinion, what percentage of patients in your ICU develop persistent critical illness?

Percentage: [enter number only]

15. What percentage of the patients who meet your definition of prolonged ICU length of stay do so because of persistent critical illness?

Percentage: [enter number only]

Persistent Critical Illness

For the purposes of this survey, we define a patient with persistent critical illness as a patient whose reason for being in the ICU is now more related to their ongoing critical illness than their original reason for admission to the ICU.

16. Of 100 patients with persistent critical illness, how many will:
(These are mutually exclusive categories)

Die before leaving the hospital?	<input type="text"/>
Die in the 6 months after discharge from hospital?	<input type="text"/>
Survive 6 months after discharge with high level support in a longterm care facility?	<input type="text"/>
Survive 6 months after discharge with significant assistance at home?	<input type="text"/>
Be alive and well at 6 months after discharge?	<input type="text"/>

Persistent Critical Illness

For the purposes of this survey, we define a patient with persistent critical illness as a patient whose reason for being in the ICU is now more related to their ongoing critical illness than their original reason for admission to the ICU.

17. How good do you believe your ICU is at caring for patients with persistent critical illness?

Poor care

Excellent care



18. How stressful does your ICU team find caring for patients with persistent critical illness?

Not at all stressful

Severely stressful



19. How cost effective do you think it is to care for patients with persistent critical illness as you do now?

Not at all cost effective

Very cost effective



Persistent Critical Illness

For the purposes of this survey, we define a patient with persistent critical illness as a patient whose reason for being in the ICU is now more related to their ongoing critical illness than their original reason for admission to the ICU.

20. What do you think are the three most important things that could be done to improve care of patients with persistent critical illness?

1.

2.

3.

Demographics & Other Information

Thank you for your time and thoughtful input. We would like to collect some basic demographic data to help understand variations in these results between various clinicians.

Your responses to these are optional, but appreciated.

21. How old are you?

- 29 or younger
- 30 - 39 years
- 40 - 49 years
- 50 - 59 years
- 60 - 69 years
- 70 or older

22. How many years of work experience do you have since completing your training?

Years (approximately):

23. How many physical beds are in the ICU where you do most of your work?

Beds:

24. Is the ICU where you do most of your work private or public?

- Private
- Public

25. Does the ICU where you do most of your work have CICM trainees?

- Yes, there are trainees
- No

26. Where is your ICU?

- New Zealand
- Australia - Australian Capital Territory
- Australia - New South Wales
- Australia - Northern Territory
- Australia - Queensland
- Australia - South Australia
- Australia - Tasmania
- Australia - Victoria
- Australia - Western Australia

Other (please specify)

27. Is there anything else you would like to tell us about these patients or this survey?

Thank you very much for your input!

This appendix was part of the submitted manuscript and has been peer reviewed. It is posted as supplied by the authors.

Appendix 2: Item Level Response Rates

Question	Answered	Skipped	Response Rate
1. This survey focuses on adult patients. Do you care for adult patients in the main ICU where you work?	101	0	100%
2. Professional Role	84	17	83%
3. In your opinion, after how many days do you think a patient should be considered as having prolonged ICU length of stay?	81	20	80%
4. What percentage of your patients do you think have a prolonged ICU stay by your definition?	81	20	80%
5. Of 100 patients with prolonged ICU length of stay, how many will:	77	24	76%
6. How good do you believe your ICU is at caring for patients with prolonged ICU length of stay?	79	22	78%
7. How stressful does your ICU team find caring for patients with prolonged ICU length of stay?	78	23	77%
8. How cost effective do you think it is to care for patients with prolonged ICU length of stay as you do now?	79	22	78%
9. How often are there delays in ICU admission because beds are already full with patients with prolonged ICU length of stay?	78	23	77%
10. Persistent Critical Illness Onset	76	25	75%
11. Conditions with prolonged intrinsic recovery time	78	23	77%
12. Persistent critical illness prototypical needs	78	23	77%
13. Persistent critical illness prototypical problems	78	23	77%
14. In your opinion, what percentage of patients in your ICU develop persistent critical illness?	78	23	77%
15. What percentage of the patients who meet your definition of prolonged ICU length of stay do so because of persistent critical illness?	78	23	77%
16. Of 100 patients with persistent critical illness, how many will:	68	33	67%
17. How good do you believe your ICU is at caring for patients with persistent critical illness?	72	29	71%
18. How stressful does your ICU team find caring for patients with persistent critical illness?	72	29	71%
19. How cost effective do you think it is to care for patients with persistent critical illness as you do now?	72	29	71%
20. What do you think are the three most important things that could be done to improve care of patients with persistent critical illness?	67	34	66%

21. How old are you?	72	29	71%
22. How many years of work experience do you have since completing your training?	72	29	71%
23. How many physical beds are in the ICU where you do most of your work?	72	29	71%
24. Is the ICU where you do most of your work private or public?	71	30	70%
25. Does the ICU where you do most of your work have CICM trainees?	71	30	70%
26. Where is your ICU? [state]	72	29	71%
27. Is there anything else you would like to tell us about these patients or this survey?	13	88	13%