

# Improving long-term outcomes after discharge from intensive care unit: Report from a stakeholders' conference

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**Background:** Millions of patients are discharged from intensive care units annually. These intensive care unit survivors and their families frequently report a wide range of impairments in their health status which may last for months and years after hospital discharge.

**Objectives:** To report on a 2-day Society of Critical Care Medicine conference aimed at improving the long-term outcomes after critical illness for patients and their families.

**Participants:** Thirty-one invited stakeholders participated in the conference. Stakeholders represented key professional organizations and groups, predominantly from North America, which are involved in the care of intensive care survivors after hospital discharge.

**Design:** Invited experts and Society of Critical Care Medicine members presented a summary of existing data regarding the potential long-term physical, cognitive and mental health problems after intensive care and the results from studies of postintensive care unit interventions to address these problems. Stakeholders provided reactions, perspectives, concerns and strategies aimed at improving care and mitigating these long-term health problems.

**Measurements and Main Results:** Three major themes emerged from the conference regarding: (1) raising awareness and education, (2) understanding and addressing barriers to practice, and (3) identifying research gaps and resources. Postintensive care syndrome was agreed upon as the recommended term to describe new or worsening problems in physical, cognitive, or mental health status arising after a critical illness and persisting beyond acute care hospitalization. The term could be applied to either a survivor or family member.

**Conclusions:** Improving care for intensive care survivors and their families requires collaboration between practitioners and researchers in both the inpatient and outpatient settings. Strategies were developed to address the major themes arising from the conference to improve outcomes for survivors and families. (Crit Care Med 2012; 40:000–000)

**KEY WORDS:** aftercare; caregivers; continuity of patient care; critical care; follow-up studies; intensive care units; outcome assessment; patient care planning; patient care team; postintensive care syndrome; posttraumatic; stress disorders; survivors

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This report summarizes the findings of a conference convened by the Society of Critical Care Medicine on September 27 and 28, 2010. The purpose of the conference was to inform stakeholders from the rehabilitation, outpatient, and community care settings of the long-term consequences of critical illness, and to initiate improvements across the continuum of care for intensive care survivors (1) and their families (2). The specific goals established when planning the conference are described in Table 3.

The long-term consequences of critical illness are growing in importance as the aging population increases demand for critical care and the short-term mortality after critical illness decreases (3–5). Annually in the United States, millions of patients are surviving critical illness (6). Many existing studies demonstrate the physical, cognitive, and mental health impairments experienced by some intensive care survivors, and the mental health impairments experienced by some family members (2, 7–9). A literature review identified intensive care unit (ICU)-based interventions that may reduce these impairments (9). However, much less is known about post-ICU interventions for improving survivor and family outcomes. Hence, the conference brought together ICU practitioners and stakeholder groups that provide care after ICU discharge. Efforts were made to obtain input from international experts along with perspectives from a range of predominantly North American disciplines, groups, and professional organizations outside of the critical care community (Table 1).

The conference began with presentations aimed at informing attendees of potential long-term consequences of critical illness and the results of post-ICU interventional research. Thereafter, stakeholder input and perspectives were shared regarding the conference goals. This report does not specifically review the long-term consequences of critical illness, as summarized elsewhere (Table 2) (2, 7, 9). This report is organized around three major themes developed from the conference discussion: raising awareness and education; understanding and addressing barriers to best practice; and identifying research gaps and resources. These themes and the entire conference report were based on a consensus of conference attendees that was developed and documented during the conference and reviewed, in detail, dur-

ing preparation of this report. Preparation of the report was an iterative process that incorporated input, and received approval, from all attendees.

## Raising Awareness and Education

Attendees believed that establishing basic nomenclature to describe post-ICU impairments is fundamental to advance awareness and facilitate education. Groups targeted for education included clinicians, survivors, families, healthcare administrators, third-party payers, and policymakers.

## Nomenclature for Post-ICU Impairments

The major categories of potential post-ICU morbidities include new or worsened impairments in physical, cognitive, and mental health. Neuromuscular weakness is an important physical impairment (10–12).

An expert consensus framework for ICU-related neuromuscular weakness has been established (13). This framework recommends the term “ICU-acquired weakness” to describe diffuse, symmetric, generalized muscle weakness (detected by physical examination and meeting-specific strength-related criteria) that develops after the onset of critical illness without other identifiable cause. Among patients with ICU-acquired weakness, the framework provides definitions for “critical illness polyneuropathy,” “critical illness myopathy,” and “prolonged neuromuscular blockade” primarily based on electromyography and nerve conduction studies. The term critical illness neuromyopathy is recommended for patients with critical illness polyneuropathy and probable or definite critical illness myopathy.

For cognitive impairments after critical illness, no widely accepted terminology exists but they are commonly referred to as “long-term cognitive impairments.” Psychiatric

Table 1. Conference attendees

Organization or Perspective Represented	Representative's Name
Society of Critical Care Medicine Conference Planning Committee	Maurene Harvey, RN MPH (Co-Chair) Judy Davidson, DNP, RN (Co-Chair) Henry Cohen, PharmD Ramona O. Hopkins, PhD Dale M. Needham, MD, PhD Craig Weinert, MD Hannah Wunsch, MD, MSc Christine Zawistowski, MD O. Joseph Bienvu, MD, PhD Christina Jones, RN, PhD Linda Denehy, PT, PhD Susan Berney, PT, PhD Doug Elliott, RN, PhD
Invited external experts	Anita Bemis-Dougherty, PT (Associate Director, Department of Practice) Christiane Perme, PT, CCS (Member) Porter C. Storey, MD (Executive Director)
American Physical Therapy Association	Gayle R. Spill, MD (Member)
American Academy of Hospice and Palliative Medicine	Marla Robinson, OTR/L, MSc, BCPR (Member)
American Academy of Physical Medicine and Rehabilitation	Susan Brady, MS (Member) Martin B. Brodsky, PhD (Member) Jeffrey B. Palmer, MD (Member-at-large) Wendy Meltzer, JD (Executive Director)
American Occupational Therapy Association	Deborah Louis, RN Elizabeth Scruth, RN David M. Schmidt, MD, PhD
America Speech-Language-Hearing Association	Sean Muldoon, MD, MPH, MS (Member) John Votto, DO (Immediate Past President)
Association of Academic Physiatrists	Andrea Harabin, PhD (Senior Scientific Advisor)
Illinois Citizens for Better Care	Carl Flatley, DDS (Founder and Chairman) Marta Render, MD (Chief, Inpatient Evaluation Center)
Kaiser Permanente Healthcare System	
Acute Long-Term Hospital Association	
National Association of Long-Term Hospitals	
National Heart, Lung, and Blood Institute	
Sepsis Alliance	
Veterans Administration Healthcare System	

Table 2. Selected potential long-term patient and family outcomes after intensive care<sup>a</sup>

Complication	Description	Selected Risk Factors	Natural History
Patient outcomes			
Pulmonary	Impairment in spirometry, lung volumes, and diffusion capacity	Diffusion capacity: duration of mechanical ventilation	Generally mild impairment with improvement during first year, but can persist 5 yrs or more
Neuromuscular/ICU-acquired weakness	Includes critical illness, polyneuropathy, and myopathy Disuse atrophy	Hyperglycemia  Systemic inflammatory response syndrome Sepsis Multiorgan dysfunction Immobility/bed rest	Polyneuropathy may recover more slowly than myopathy; can extend to 5 yrs
Physical function	Impairment in ADL (ADL/IADL) and 6-min walk distance	Systemic corticosteroids -ICU-acquired illnesses Slow resolution of lung injury Age Preexisting IADL impairment	Some improvement in ADL within months, but impairments may be seen in ADL at 1 yr and in IADL at 2 yrs Long-lasting impairment in 6-min walk distance vs. population norms
Psychiatric	Depression	Traumatic/delusional memories of ICU, sedation, psychiatric symptoms at discharge, impairment of physical function	May decrease over first year
Symptoms	Posttraumatic stress disorder  Anxiety	Sedation, agitation, physical restraints, traumatic/delusional memories Unemployment, duration of mechanical ventilation Overall risk factors: female gender, younger age, less education, and pre-ICU psychiatric symptoms, and personality	Little improvement in first year  May persist past first year
Cognitive	Impairments in memory, attention, executive function, mental processing speed, visuo-spatial ability	Lower pre-ICU intelligence ICU delirium Sedation Hypoxia Glucose dysregulation	Significant improvement during first year, with residual deficits up to 6 yrs later
Family outcomes			
Psychiatric	Depression	Overall risk factors: female gender, younger age, less education, pre-ICU psychiatric symptoms, and personality, distance to hospital, restricted visiting	Depression and anxiety decrease over time, but are higher than population norms at 6 months
Symptoms	Posttraumatic stress disorder  Anxiety  Complicated grief	Dissatisfaction with communication, ICU physician perceived as “uncaring,” passive preference for decision-making, mismatch between involvement in decision-making and preference Severity of illness not associated with development of symptoms Complicated grief is worse when family does not have knowledge of patient’s wishes In pediatric ICU, paternal stress after discharge is associated with child stress in pediatric ICU	Posttraumatic stress disorder and complicated grief can persist 4 yrs or more after death or discharge and may not decrease over time

ADL, activities of daily living; IADL, instrumental activities of daily living; ICU, intensive care unit.  
<sup>a</sup>Adapted, with permission, from previous publication (9).

Table 3. Goals of the conference

Understand the long-term outcomes of intensive care patients and their families, and identify gaps in the literature with respect to these outcomes  
Identify stakeholders for sharing perspectives on the scope and nature of these long-term outcomes and develop relationships that lead to collaboration  
Identify strategies and funding sources to better meet patient and family needs, including professional education, resource development, community outreach, and research  
Explore how stakeholders can contribute to improving long-term outcomes of intensive care patients and their families after discharge from the hospital

symptoms occurring after critical illness (e.g., depression, anxiety, posttraumatic stress disorder) should be classified and diagnosed using existing sources (e.g., Diagnostic and Statistics Manual of Mental Disorders).

Attendees agreed that given the high frequency of multiple impairments after critical illness, awareness would be improved by use of a single term to identify

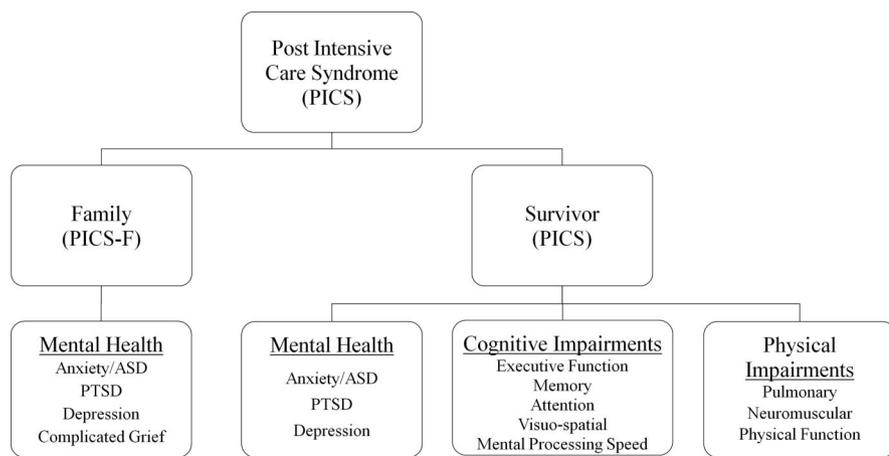


Figure 1. Postintensive care syndrome (PICS) conceptual diagram. *ICU*, intensive care unit; *ASD*, acute stress disorder; *PTSD*, posttraumatic stress disorder.

the presence of one or more of these impairments. The term “postintensive care syndrome” (PICS) was agreed on as the recommended term to describe new or worsening impairments in physical, cognitive, or mental health status arising after critical illness and persisting beyond acute care hospitalization. The term PICS could be applied to a survivor or family member (Fig. 1). Because of the co-occurrence of problems across these three categories of health status, attendees believed that a syndrome-based term is appropriate. Attendees hoped that creation of the PICS term would facilitate awareness among stakeholders, prompt screening for these problems by outpatient clinicians, and lead to greater investigation into the epidemiology, pathophysiology, treatment, and prognostication of the specific morbidities that follow critical illness, as has occurred with the term “postcardiac arrest syndrome” (14, 15). Through defining PICS, conference attendees did not intend for investigation, diagnosis, and treatment of specific impairments to be overlooked in favor of any collective therapy for multiple impairments across all survivors and families.

### Awareness and Education Strategies

Several strategies were identified for raising awareness and educating stakeholders, including publication of conference proceedings, review articles (9) and newsletters, and the creation of a multifaceted tool kit (e.g., fact sheet, annotated bibliography, slide presentation). Identifying a famous ICU survivor to serve as a national spokesperson was identified as a long-term goal for raising awareness.

Attendees identified specific barriers to awareness. The largest barrier was the existence of “silos” among clinician groups. These silos include the barriers between critical care and rehabilitation specialists working within the ICU as well as gaps that occur, even within a clinical specialty, when a patient moves from the ICU to ward and outpatient settings. Bringing together relevant organizations and clinical disciplines in this conference is a first step in facilitating integration across these silos.

### Understanding and Addressing Barriers to Best Practice

Conference attendees identified barriers that challenge providing coordinated and comprehensive care for patients and families after discharge. The major issues discussed were the context of medical care for ICU patients and the underutilization of rehabilitation specialists in improving post-ICU patient outcomes.

### The Context of Medical Care for ICU Patients

Critical care has historically been provided in isolation from patients’ primary care providers (16). ICU discharge notes and treatment plans frequently focus on organ-specific issues, with less focus on functional impairments. Furthermore, on discharge from the ICU, survivors frequently have impaired memory regarding their ICU stay. Sudden acquisition of numerous new and unrecognized functional and cognitive impairments that have complex multifactorial causes and unclear treatments can be confusing to sur-

vivors, families, and clinicians (9, 10, 17–19). The current level of discharge planning and communication with survivors, families, and clinicians may be inadequate given our current knowledge of the magnitude of post-ICU impairments and patients’ potential stress and cognitive impairment (20, 21). Furthermore, there are important deficits in primary care clinicians’ awareness and preparation to provide and coordinate care for survivors. Furthermore, outpatient providers are often unable to provide feedback to ICU staff regarding survivors’ long-term outcomes, creating a potential missed opportunity for education and process improvement for critical care clinicians.

### Underutilization of Rehabilitation Specialists and Potential Solutions

Physiatrists (physicians specializing in physical medicine and rehabilitation) and other rehabilitation clinicians (physical therapists, occupational therapists, speech language pathologists, and psychologists) attending the conference agreed that physiatry and the rehabilitation team are important for coordinating post-ICU care for survivors. Despite the expertise of rehabilitation clinicians in addressing impairments commonly experienced by survivors, several barriers to their integration in post-ICU care were identified. These clinician groups may have limited awareness of the possible long-term consequences of critical illness. ICU survivors do not have a recognized rehabilitation pathway, such as traumatic brain injury or stroke. Existing clinical training programs for rehabilitation clinicians have limited exposure to critical care issues. Ideas for addressing these barriers include having a rehabilitation-focused group within the Society of Critical Care Medicine and having the rehabilitation professional societies offer educational programs and specialist certification in critical care/acute care for interested members. ICU follow-up clinics also may help integrate critical care and rehabilitation expertise to better-identify and manage post-ICU morbidities (22).

Attendees recommended examining successful rehabilitation and recovery models from other areas in medicine, such as stroke rehabilitation or oncology (23, 24). Similar to critical care, oncology involves complex medical care and previously lacked focus on survivors’ long-

term outcomes. However, for more than two decades, strong clinical and research advocacy has focused interest on understanding and improving the long-term complications of cancer and oncology care. This effort has included better integration of oncology clinical programs with primary care providers, and research funding and leadership from the National Cancer Institute and the Centers for Disease Control and Prevention (16). Rehabilitation programs for chemical dependence were also discussed given their emphasis on recovery as a process requiring long-term commitment from survivors, family/friends, and clinicians. Finally, the expertise of the Veterans' Affairs healthcare system in the investigation and management of traumatic brain injury, posttraumatic stress disorder, and cognitive rehabilitation could be applied to intensive care survivors and families.

Funding for rehabilitation care poses several potential barriers to survivors' recovery. Current requirements for insurance coverage for acute inpatient rehabilitation in the United States generally specify that patients must be able to tolerate a minimum of 15 hrs of rehabilitation services per week. However, because of severe deconditioning, many ICU survivors may be unable to initially tolerate this intensity of rehabilitation. Consequently, they may be discharged to subacute rehabilitation facilities once their acute medical issues are resolved, or to long-term acute care hospitals if greater medical specialization is required. The complexity and magnitude of the rehabilitation needs of post-ICU patients may exceed the capabilities of some facilities and result in a delay or inability of survivors to reach their full potential during recovery.

Regulatory requirements for acute inpatient rehabilitation in the United States frequently require that at least 60% of patients have a primary or secondary diagnosis that is among a list of diagnoses deemed appropriate. Although anoxic brain injury and critical illness polyneuropathy are qualifying diagnoses, other conditions common in ICU survivors, such as delirium and ICU-acquired weakness, are not. This 60% rule can be an important barrier to admitting ICU survivors for acute inpatient rehabilitation.

For outpatient rehabilitation services, funding-related barriers also exist. Survivors may have limited or no insurance coverage for these services, or they may

be unable to arrange transportation for their appointments. An ideal setting for survivors would be comprehensive multidisciplinary outpatient ICU follow-up clinics that provide assessments from all relevant clinician groups and that coordinate a plan for rehabilitation care. However, such clinics often require funding from foundations and disease-specific associations (e.g., cystic fibrosis, [www.cff.org/LivingWithCF/CareCenterNetwork/](http://www.cff.org/LivingWithCF/CareCenterNetwork/)) to operate. Finally, insurance may not cover the cost of medications prescribed on discharge, resulting in nonadherence to treatment plans.

### **Identifying Research Gaps and Resources**

Uncertainty exists regarding the best approaches for providing post-ICU care. A small noncontrolled study of ICU survivors in the United Kingdom demonstrated that a 6-wk program consisting of a 2-hr outpatient class and two unsupervised home-based exercise sessions per week showed feasibility and improvement in walk tests and anxiety and depression scores (25). A randomized trial of U.K. ICU survivors evaluated a rehabilitation manual that included self-directed exercises, psychological advice, and information about the after-effects of critical illness and the importance of smoking cessation. This trial demonstrated improved physical function-related quality of life at 6 months, a trend toward decreased depression symptoms, and increased smoking cessation (26, 27). However, a randomized trial of home-based physical rehabilitation (including a handbook, in-person evaluation, and personalized rehabilitation programming) demonstrated no benefits in physical function-related quality of life or secondary outcomes in an Australian setting (28). Important differences in patient characteristics (e.g., longer ICU stay in U.K. study) and less access to routine rehabilitation therapy in the United Kingdom may explain differences in findings compared with the Australian trial. Furthermore, a randomized trial of nurse-led outpatient follow-up after ICU in the United Kingdom demonstrated no benefit in quality of life or secondary outcomes (29). Finally, giving survivors diaries documenting day-to-day details of their ICU stay after their discharge demonstrated a reduction in posttraumatic stress disorder and symptoms of anxiety and depression (30, 31).

With this limited base of clinical trials for outpatient management of survivors, attendees identified important research gaps related to the mechanisms and epidemiology of post-ICU morbidities and specific patient subgroups and research areas.

### **Mechanisms of Post-ICU Morbidities**

There is a lack of basic science and translational research to understand post-ICU impairments. Given the number of domains that may be impaired, the multiple likely mechanisms of injury associated with critical illness and the variety of possible interventions, conducting investigations with findings applicable to all survivors is challenging. Some mechanisms common to critical illness, such as hypoxia, hypotension, inflammation, glucose dysregulation, catabolism, and nutritional deficiencies, may lead to multiple impairments that interact with each other (32–38). Treatments provided during critical illness, including endotracheal intubation, bed rest/immobilization, frequent use of benzodiazepines, other sedatives, and physical restraints, and interruption of the sleep-wake cycle also may contribute to post-ICU impairments (30, 39–48). Greater research is needed to understand common mechanisms and specific pathologic processes and associated mechanisms of individual impairments.

### **Epidemiology of Post-ICU Impairments**

Epidemiologic studies are needed to better define the scope of post-ICU impairments and associated costs of care. Such data are needed at the individual patient level to identify the specific types of patients who are at greatest risk for specific impairments and factors affecting the trajectories of recovery. At the hospital level, research is needed to create a "business case" for investment in rehabilitation services for ICU patients (49). Finally, at the regional and national level, epidemiologic research is required to aid in health policy and planning, and in coverage decisions by insurers.

Observational studies and phase II and III trials are required. Observational research is needed to understand which patient subgroups may respond, may not respond, or may be harmed by interventions such as intensive rehabilitation in,

or immediately after, the ICU. Prospective cohort studies also allow simultaneous examination of multiple exposure–outcome associations to permit efficient screening of potentially beneficial therapies that can be more definitively investigated in subsequent randomized trials (50, 51). When compared to other literature (e.g., oncology), critical care has little research prospectively evaluating long-term patient outcomes extending beyond 1 or 2 yrs after critical illness (16). The few existing studies with data beyond 2-yr follow-up have been instrumental in demonstrating areas of true long-term morbidities (52), and the potential recurrence of morbidities in survivors followed-up for 5–8 yrs after ICU discharge (16, 53, 54). These existing studies should be supplemented with additional investigations to understand the generalizability of findings to larger samples and other geographic settings. Finally, information regarding post-ICU events experienced by survivors is necessary to more fully understand the post-ICU recovery process (55).

To help ensure comparability of findings across studies, attendees emphasized the importance of gaining consensus on a standard set of outcome measures, which have been validated in survivors. Such consensus has been helpful in measuring quality of life outcomes (56–58), but much more work is required for other outcome measures. Instruments used in physical medicine and rehabilitation may need to be evaluated. Expanding previous systematic reviews of instruments used in critical care and instruments' test characteristics (i.e., reliability, validity, and responsiveness), along with a consensus conference, would be valuable (7, 59, 60).

### **Specific Patient Subgroups and Research Areas**

Intensive care patient subgroups for future research include geriatrics (61), pediatrics, and those with chronic critical illness or preexisting chronic disease (physical, cognitive, or psychiatric). These groups have received relatively less focus within existing ICU research. Strategies to prevent post-ICU morbidities in families are also underexplored (62–64).

Five additional research gaps were identified. First, a gap exists in understanding how to effectively and efficiently screen patients for specific post-ICU impairments to determine the need for further diagnostic work-up and treatment.

Little evidence exists to support current informal recommendations (18) and U.K. guidelines for post-ICU care (65). Further investigation is needed regarding the design of post-ICU interventions (29, 66). Second, despite the emerging body of research investigating the outcomes of physical rehabilitation interventions conducted during and after ICU stays (43, 66–70), there is little research evaluating the best methods for survivor cognitive rehabilitation and for psychiatric interventions. Given the link between a patient physical function and cognition and mental health (38, 71–73), interventions and outcome measures should be coordinated across the various post-ICU impairments. Third, both psychological interventions and complementary medicine interventions (including cognitive behavioral therapy, music therapy, and guided imagery) may be useful to address pain, anxiety, and stress (74). Fourth, given major sleep-related issues experienced by patients during and after ICU stays, the connection of sleep disorders to physical, cognitive, and mental health should be evaluated (75). Finally, problems related to the larynx, voice, and swallowing after extubation and their connection to long-term impairments represent another research gap (39, 44, 76).

### **Potential Research Resources**

Given the multidisciplinary nature of critical illness and recovery, the National Institutes of Health support critical care research at a number of its 27 Institutes and Centers. A NHLBI workshop focused on future clinical research priorities for acute lung injury recommended that evaluating the impact of interventions on long-term quality of life and functional outcomes should be a fundamental part of phase III trials (3). Other institutes with interest in aspects of critical care research include aging (61), general medical sciences, nursing, allergy and infectious diseases, child health, diabetes, and digestive and kidney diseases. One challenge with National Institutes of Health funding is the 5-yr cycle of funding, which makes studies of long-term outcomes difficult to design and fund. The federally funded Patient-Centered Outcomes Research Institute is being planned to provide direction in the selection and conduct of comparative clinical effectiveness research, which may influence clinical research directions for post-ICU impairments. The Department of

Veterans Affairs also has funded ICU long-term outcomes research and is a leader in research in posttraumatic stress disorder. Finally, conference attendees agreed that their professional societies should explore adding critical illness-related rehabilitation to their research agenda for society-based research funding opportunities.

### **Limitations**

There are several limitations of this conference report. First, although research and educational issues were discussed, a complete agenda for improving these issues could not be developed during the 2-day conference. Activities are currently ongoing within the organizations represented at the conference to address specific issues raised. Second, neonatal, pediatric, and family aspects of PICS were not discussed in detail. This is caused, in part, by underrepresentation among conference attendees. Patient and family perspectives are particularly important in better understanding of the awareness and education issues reported on, including use of terminology such as PICS. Third, despite substantial efforts to engage other stakeholders, there was also a lack of representation from primary care practitioners, geriatricians, hospitalists, social workers, care coordinators, policymakers, and payers. Efforts are ongoing to engage these groups in future activities. Finally, the methods used to create the conference report did not include formal consensus methods. The report was a synthesis of the conference discussions that was revised and agreed on by the predominantly North American stakeholder groups and may not be generalizable outside of this context. Despite this limitation, we believe the conference is unique in bringing together a broad group of non-ICU professional organizations that actively contributed important perspectives regarding the conference objectives.

### **CONCLUSION**

With a growing number of patients surviving critical illness, there is an urgent need to more fully address the long-term consequences of intensive care for survivors and their families. This SCCM conference focused on improving these long-term consequences and discussed three major issues in the field: raising awareness and education, including introducing the term PICS to describe these long-term consequences, identify

ing barriers and solutions for comprehensive post-ICU rehabilitation, and identifying research gaps and resources across the spectrum from basic science to clinical research. Through the efforts of SCCM, in collaboration with conference stakeholder groups, these issues are being systematically addressed to help improve the long-term outcomes of critical illness for survivors and their families.

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