

# Exploring the Scope of Post-Intensive Care Syndrome Therapy and Care: Engagement of Non-Critical Care Providers and Survivors in a Second Stakeholders Meeting

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**Background:** Increasing numbers of survivors of critical illness are at risk for physical, cognitive, and/or mental health impairments that may persist for months or years after hospital discharge. The

post-intensive care syndrome framework encompassing these multidimensional morbidities was developed at the 2010 Society of Critical Care Medicine conference on improving long-term outcomes after critical illness for survivors and their families.

**Objectives:** To report on engagement with non-critical care providers and survivors during the 2012 Society of Critical Care Medicine post-intensive care syndrome stakeholder conference. Task groups developed strategies and resources required for raising awareness and education, understanding and addressing barriers to clinical practice, and identifying research gaps and resources, aimed at improving patient and family outcomes.

**Participants:** Representatives from 21 professional associations or health systems involved in the provision of both critical care and rehabilitation of ICU survivors in the United States and ICU survivors and family members.

**Design:** Stakeholder consensus meeting. Researchers presented summaries on morbidities for survivors and their families, whereas survivors presented their own experiences.

**Meeting Outcomes:** Future steps were planned regarding 1) recognizing, preventing, and treating post-intensive care syndrome, 2) building strategies for institutional capacity to support and partner with survivors and families, and 3) understanding and addressing barriers to practice. There was recognition of the need for systematic and frequent assessment for post-intensive care syndrome across the continuum of care, including explicit "functional reconciliation" (assessing gaps between a patient's pre-ICU and current functional ability at all intra- and interinstitutional transitions of care). Future post-intensive care syndrome research topic areas were identified across the continuum of recovery: characterization of at-risk patients (including recognizing risk factors, mechanisms of injury, and optimal screening instruments), prevention and treatment interventions, and outcomes research for patients and families.

**Conclusions:** Raising awareness of post-intensive care syndrome for the public and both critical care and non-critical care clinicians will inform a more coordinated approach to treatment and support during recovery after critical illness. Continued conceptual development and engagement with additional stakeholders is required. (*Crit Care Med* 2014; XX:00–00)

**Key Words:** caregiver; cognitive impairment; collaborative care; critical illness; family; mental health; physical activities; post-intensive care syndrome; rehabilitation

This report summarizes the outcomes from a second stakeholder meeting on post-intensive care syndrome (PICS), aimed at improving outcomes for patients and families following critical illness. "The term 'post-intensive 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 could be applied to a survivor (PICS) or family member (PICS-F)" (1).

The meeting was convened by the Society of Critical Care Medicine (SCCM) with key stakeholders representing both non-critical care and critical care disciplines as well as patient

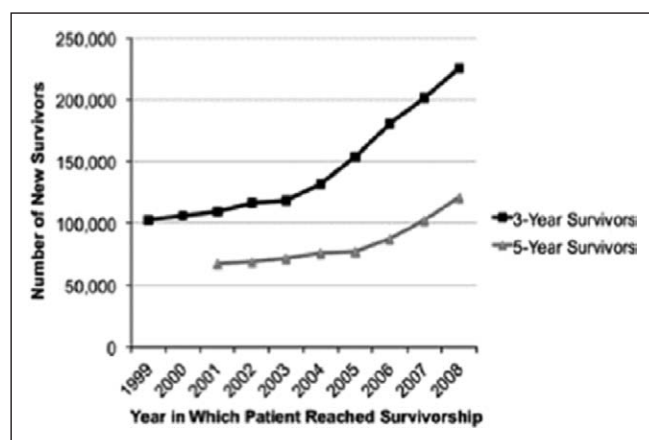
advocates (survivors and family members). Stakeholders represented professional organizations, health systems, and groups involved with post-ICU patient care, including recovery and rehabilitation of survivors of critical illness, across a range of settings including inpatient, outpatient, and community care. Both survivors and family members affected by critical illness attended and provided their perspectives and advocacy.

## BACKGROUND

Reduced mortality and the increasing prevalence of critical illness have resulted in a large and increasing numbers of survivors (2). Each year, approximately 800,000 people develop a critical illness requiring mechanical ventilation and admission to an ICU in the United States; across every age group, a majority of patients survive their critical illness to hospital discharge (3). For example, among Medicare patients alone, by 2008, over 1 million patients were hospitalized with severe sepsis; a clear majority of whom survive their acute critical illness, with survival rates increasing over time due to improved care (2) (Fig. 1). Importantly, there are now over 600,000 survivors of severe sepsis alone among older Americans ( $\geq 65$  yr) (2), but it is unknown how many suffer the effects of PICS.

As with other serious illnesses where advanced treatments push the boundaries of survival (4), survivors of critical illness can undergo profound changes in their lives as a result of their experience, with many having some form of deficit in one or more domains (5) of physical (6, 7), psychological (8–10), or cognitive functioning (9, 11–13). Family members may also suffer from this critical illness event, with depression (14) or other enduring effects (15). For survivors, these physical, mental health, and cognitive morbidities can be newly arising or worsening after critical illness (13, 16, 17), are frequently severe, adversely affecting an individual's functioning (e.g., employment and quality of life), and may persist for months or years after hospital discharge (5, 7, 13, 16, 17).

As the critical care community's awareness of PICS increases, it is important to inform other stakeholders affected by, or involved in, the continued care for people with PICS, including patients, families, and relevant disciplines in hospital systems



**Figure 1.** New 3- and 5-year survivors after severe sepsis. Reproduced with permission from Iwashyna et al (2).

and the posthospital community. The burden of critical illness for individuals and their families has been described as a continuum lasting from before ICU admission to months or years after hospital discharge (18). The PICS (1) and PICS-F (19) framework highlight physical, cognitive, and mental health domains identified from numerous investigations examining outcomes for ICU survivors (20–25) and their families (19, 26).

Of note, a similar general construct of “posthospital syndrome” has also recently been proposed, reflecting an acquired transient period of generalized risk related to a patient's acute hospitalization, preexisting comorbidities, and new hospitalization-related stressors. These hospitalization-related stressors include physical deconditioning, disruptions to sleep, inadequate nutrition, medication effects, and cognitive impairments such as confusion or delirium (27). Mitigating risks for developing these hospitalization-associated disabilities, particularly for older adults, require systematized assessment and documentation of prehospital functioning and of changes that occur during hospitalization, using brief screening assessments of mobility and cognition, and early patient-centered discharge planning (28). Importantly, systematic and frequent assessments for these deficits are particularly salient within the context of a critical illness, where survivors have the highest risk for life-altering physical, mental, and cognitive impairments following hospitalization (17, 29, 30).

The presence of these clinical manifestations reflective of the PICS/PICS-F framework may be more than just transient events (19, 29), with symptoms evident as long as 5 years following hospital discharge (7) and permanent for some survivors. Identifying and profiling PICS characteristics to non-critical care providers, survivors, their families and informal caregivers, and the broader public is therefore an important step in developing the necessary support structures and understanding for this growing cohort of ICU survivors.

## MEETING

### Approach

The SCCM PICS stakeholder meeting was held on September 24–25, 2012. Given the context of an evolving but currently limited evidence base, we decided, a priori, to elicit broad stakeholder agreement for any meeting outcomes and recommendations. The meeting structure included plenary sessions on the current state of the science and personal stories from survivors, break-out sessions in task groups to brainstorm ideas and develop recommendations and action plans, and then reports back to all participants for approval.

### Participants

In preparation for the meeting, members of the SCCM PICS Task Force identified survivors, clinicians, and scientists as well as representatives of relevant professional organizations involved in the evaluation, treatment, and support of intensive care survivors across the continuum of care, including acute inpatient and outpatient rehabilitation, skilled nursing facilities, long-term acute care hospitals, and outpatient care settings.

Representatives from 21 professional associations or health systems involved in the provision of critical care, non-critical care, or rehabilitation services attended the meeting. Importantly, founders of two patient advocacy groups representing ICU patients and families also participated as patient advocates (31) (**Table e1**, Supplemental Digital Content 1, <http://links.lww.com/CCM/B16>).

### Task Groups

Three task groups, similar to the inaugural 2010 PICS meeting (1), were formed to address the following issues: raising awareness and education of PICS, understanding and addressing barriers to practice, and identifying research gaps and resources. Each group comprised clinicians and researchers from a variety of professional organizations and ICU survivors. Prior to the meeting, task groups composed of attendees from the first conference worked together, remotely, to create draft reports outlining areas requiring additional development, which served as a starting point for this second stakeholder meeting.

### MEETING OUTCOMES

Action plans for each task group were developed and subsequently approved by all task force members at the conclusion of the meeting; **Table 1** highlights the tactics identified by each task group for implementation. Some of the key issues for continuing task group work are discussed further below according to the following topic areas: public awareness, information resources, professional awareness, functional reconciliation, and recommendations for research.

#### Public Awareness

The published definition of PICS (1) was considered by the “Education” task group to require some modification to improve clarity and promote optimal use within the public domain. The proposed lay definition for use in a public awareness context was:

*Post intensive care syndrome (also called PICS) describes new or worse health problems after critical illness that remain after you leave the hospital. These problems can be with your body, thoughts, feelings or mind and may affect you or your family.*

We see this user-friendly lay definition to be important in informing the general public, including family, friends, neighbors, work colleagues, and employers. The definition will continue to evolve with testing and use in the public domain.

#### Information Resources

Resource options for raising public awareness of PICS were examined, and these focused on designing an information brochure, related videos, and social media material (see <http://www.mycicare.org/Adult-Support/Pages/Post-intensive-Care-Syndrome.aspx>). Relevant videos and social media material are also accessible by searching “Post intensive care syndrome” on

the SCCM intranet. Similarly, with important input from survivor representatives, the SCCM brochure on leaving the ICU (see <http://www.mycicare.org/Adult-Support/Pages/Leaving-the-ICU.aspx>) was modified to include a checklist of questions to identify when symptoms should be reported to the patient or family member’s physician for follow-up, treatment, or referral.

#### Professional Awareness

Broad dissemination of information and awareness of PICS to a diverse range of health professionals and their professional organizations involved in the treatment and care of ICU survivors and their families is imperative; this report forms part of this effort to increase awareness. Meeting participants from non-critical care disciplines were encouraged to raise PICS awareness by submitting proposals to deliver PICS presentations at their own forthcoming conferences.

Of note, participating ICU survivors indicated that their own informational needs from health professionals varied over the course of their recovery, highlighting the need for different resources and dissemination methods to be developed. Given that patients may initially be unable to process complex information at their ICU or acute care hospital discharge, providing understandable information to family members at these times is particularly important. Although post-ICU clinics are one potential method to address these patient needs (32), there is currently mixed evidence on their effectiveness on patient outcomes (33, 34), and funding and resourcing this type of service in the United States needs further exploration and evaluation. Continued development of information resources and dissemination methods therefore need to be funded and evaluated regarding their effectiveness.

#### Functional Reconciliation

The “Barriers” task group recommended developing and promoting the concept of “functional reconciliation,” with formal comparison of a patient’s functional ability prior to hospitalization with their current status at all transitions in level of care within institutions and between institutions and outpatient/community resources. This new concept is similar to “medication reconciliation,” a well-known element of the U.S. Joint Commission standards (35). This type of mechanism for brief standardized assessment of function for ICU patients would be valuable in identifying and managing symptoms of PICS across the continuum of care.

A draft flowchart for use in assessing level of risk during transitions of care is illustrated in **Figure 2**. Risk assessment is a key element to ensure that patient safety and continuity of care are highlighted during transfers or transitions to different care levels within or between healthcare organizations. The figure also highlights considerations for referral and patient education/information.

There is currently, however, limited agreement on the use of standardized functional measures that demonstrate reliability, validity, and utility for clinical use across the entire continuum of care from the ICU to home environment. Potential assessment instruments therefore need further investigation.

**TABLE 1. Postconference action plan**

Task Group	Tactic
Awareness and education	<p>Raise clinician and public awareness to achieve:</p> <ul style="list-style-type: none"> <li>• Appropriate ICU treatment (PICS prevention or amelioration through ABCDE bundle [54] plus newly proposed “FGH” addition to the bundle<sup>a</sup>)</li> <li>• Optimization of handoffs between levels of care and practitioners (appropriate referrals and continued care)</li> <li>• Optimization of access to care throughout the continuum of care</li> </ul> <p>Modify PICS tool-kit to include a PICS brochure for patients and families (Society of Critical Care Medicine Patient Education committee)<sup>b</sup></p> <p>Create videos about PICS and PICS-F<sup>b</sup></p> <p>Create Wikipedia PICS page<sup>b</sup></p> <p>Develop a “stakeholders supporting stakeholders” virtual space</p>
Barriers to practice	<p>Develop and promote the concept of a functional reconciliation checklist</p> <ul style="list-style-type: none"> <li>• Checklist to include physical, cognitive, and mental health domains</li> <li>• Checks at all transitions of care from ICU through to community reintegration</li> <li>• Inclusion of case managers to facilitate transition of care and referral to appropriate providers</li> </ul> <p>Develop and promote patient and primary care provider educational information to include</p> <ul style="list-style-type: none"> <li>• PICS risk factors</li> <li>• Issues for triggering referrals for additional medical care</li> </ul> <p>Advocate for the development of an ICD code for PICS to facilitate appropriate care and setting:</p> <ul style="list-style-type: none"> <li>• Consider for ICD version 11</li> <li>• Consider engaging terminologists for inclusion in Systematized Nomenclature of Medicine Clinical Terms language</li> </ul>
Research	<p>Partnering for research with other national organizations regarding PICS:</p> <ul style="list-style-type: none"> <li>• Critical Care Societies Collaborative research group make contacts with the NIH and other partner organizations</li> <li>• Partner organizations to promote PICS in their conferences</li> </ul> <p>Identify funding sources, including NIH institutes, Agency for Healthcare Research and Quality, Patient Centered Outcomes Research Institute, and foundations, including focus on:</p> <ul style="list-style-type: none"> <li>• Patient perspective and outcomes</li> <li>• Transition of care including link with primary care</li> </ul> <p>Patient involvement in research, including qualitative and mixed methods</p> <p>Develop a national database for dataset related to PICS</p> <p>Add long-term outcome measures to existing studies</p>

PICS = post-intensive care syndrome, ICD = *International Classification of Diseases*, NIH = National Institutes of Health.

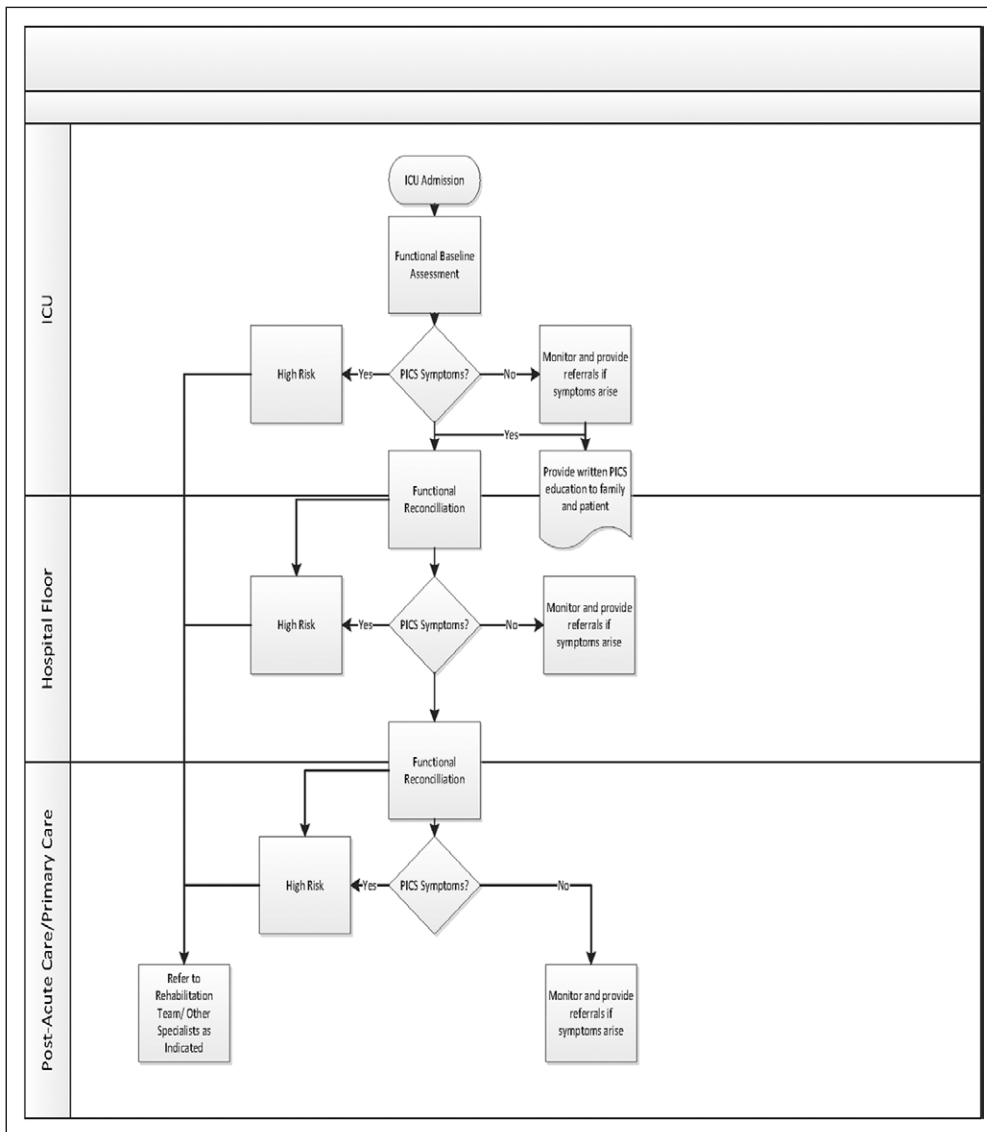
<sup>a</sup>ABCDEFH: Awakening and Breathing Coordination, Delirium Assessment, Early Mobility, Follow up referrals, family inclusion, functional reconciliation, Good hand-off communication, Hand family written information.

<sup>b</sup>Activities completed.

For example, one instrument with some emerging validity and utility for patients in hospital floor and posthospital contexts examines daily activity and mobility deficits (36), but additional research is required with a critical care cohort including in-ICU assessments.

### Research Gaps for Components of PICS

A range of topic areas identified by the research task group highlighted where further evidence is required to support our understanding of patient recovery from PICS. **Figure 3** illustrates research areas as they relate to the critical illness and recovery



**Figure 2.** Flowchart of risk assessment. PICS = post-intensive care syndrome.

trajectory, categorized as: 1) characterization and identification of at-risk patients; 2) areas for prevention and treatment interventions; and 3) outcomes research for patients and families.

Of note, it was reinforced that research strategies include a patient-centered focus, incorporate qualitative and mixed methods approaches where appropriate to enable full exploration of patient and family experiences and outcomes, and include long-term outcome measures into existing studies, such as ICU-based randomized trials (5, 37). Development of system, regional, and national datasets of patient-level data across the continuum of illness and recovery would benefit both research and practice evaluations. This scope and level of routinely collected data would improve current limitations in study methods, where sample sizes, enrollment bias, and loss to follow-up all limit internal and external validity of findings.

As also illustrated in Figure 3, topics on methodology (e.g., patient retention strategies, psychometric testing, and economic analyses) are required to advance the state of science in concert

with patient outcome studies. The 2012 conference also discussed developing strategies to overcome the research-related barriers identified at the 2010 meeting and identifying potential roles for organizations at the 2012 conference in executing identified research strategies.

### Funding for Critical Care Research

The multidisciplinary nature of critical care practice and research is reflected in the National Institutes of Health (NIH)-supporting research across 27 institutes and centers (38). The research task group recommended that partnering with other national organizations is needed, with the Critical Care Societies Collaborative (CCSC) research group leading this initiative to encourage research funding from a variety of NIH institutes, and other sources (e.g., foundations or the Patient-Centered Outcomes Research Institute), that focus on patients and on transitions of care or links with primary care. This current diversity of funding sources may however be potentially detrimental in focusing and coordinating critical care research endeavors (39). Creating an NIH office of critical care

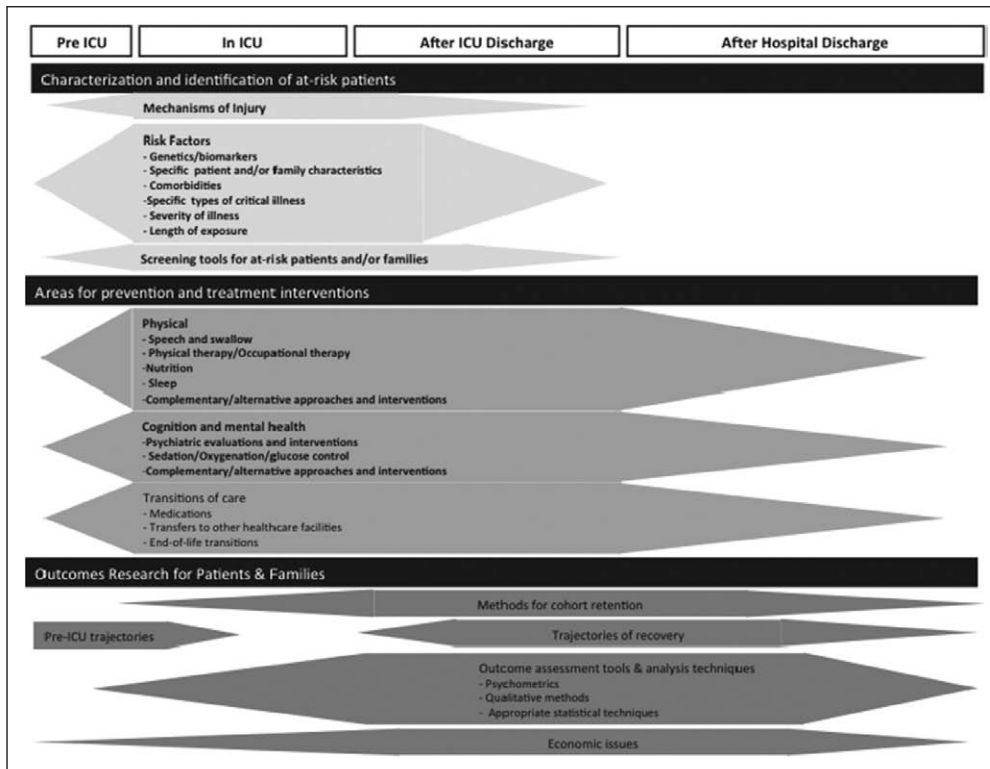
research would provide an appropriate emphasis, with a precedent already in existence with the Office of Emergency Care Research (40). The CCSC is, inter alia, progressing with this initiative (39).

### ICD Code for PICS

Developing the PICS framework as a constellation of signs and symptoms under the umbrella of a new clinical “syndrome” provides the potential opportunity for appropriate funding of actual clinical practices being provided to survivors. Introduction of an explicit diagnostic code for PICS would enable dedicated funding for case/care managers to target appropriate care for these patients. The ICD-11 version could be targeted, with input from a terminologist familiar with the Systematized Nomenclature of Medicine Clinical Terms language.

### DISCUSSION

A substantial but unknown proportion of survivors of a critical illness are at risk of developing mental health, cognitive, and/or



**Figure 3.** Research areas for post-intensive care syndrome where further evidence is required.

physical impairments. The PICS framework encompasses this constellation of sequelae. Increased public and both noncritical care and critical care health professionals' awareness and education are an important initial step to progress our collective understanding of PICS manifestations (41).

### Key Outcomes

This meeting broadened the scope of our understanding of PICS by engaging non-critical care professionals and representatives from health systems, agencies and professional organizations, and patient advocates. The concept of “functional reconciliation” for use during transitions of care was proposed to improve continuity of care and interprofessional communications for these often-complex patients. An action plan for the PICS taskforce was developed and approved, and specific areas requiring systematic research were identified.

Importantly, systematic recognition of mental health, cognitive, and/or physical impairments related to PICS is required during transitions of care settings across the continuum of critical illness and recovery. More research is required to identify optimal screening instruments, mechanisms, and risk factors for PICS and to evaluate interventions in the ICU and post-ICU to prevent or ameliorate PICS. Our task groups are continuing to work together to implement elements of their action agendas.

### Implications for Practice and Policy

A range of practice implications is reported here. Of note, more public awareness and education resources are required to

better inform ICU survivors, their families, and caregivers of the risks for PICS. Similarly, healthcare professional awareness and education are also necessary to support changes in practice for critical care, acute care, rehabilitation, and community settings. As this work evolves, explicit documentation (“functional reconciliation”) and communication (“handoffs”) resources can be developed and evaluated in clinical practice, particularly during transitions of care (42), as an important patient care and safety issue for patients at risk of PICS. Others have identified similar needs during transitions of care in the United Kingdom context (43). These practice recommendations will require early adopters, with preparation, implementation, and evaluation clearly

documented and reported, to inform the evolving evidence base for managing PICS.

The issues of PICS diagnostic codes and appropriate reimbursement for screening, prevention, and treatment of physical, mental, and cognitive impairments need further discussion, advocacy, and development with relevant authorities.

### Strengths and Limitations

This meeting had broad representation of stakeholders. Importantly, four participants were survivors of a critical illness, with two representing ICU survivor advocacy groups. These participants provided valuable insights into the challenges for patients and their loved ones during recovery from catastrophic illnesses and injuries. Engaging these perspectives reinforced that our evolving PICS framework is patient centered and addresses significant issues for both patients and their families.

Twenty-one professional associations or health systems were also represented. This engagement with relevant non-critical care disciplines provided important perspectives from content experts across the recovery trajectory. Despite this strong participation, there were key stakeholder organizations unable to attend or who declined our invitation to participate. There may also be additional viewpoints from other specialty ICU areas (e.g., cardiac surgery, trauma, transplant, and neurologic) with differing perspectives.

Other more community- or social-based perspectives of recovery may not yet be identified and included in our action plan. Although not addressed in this meeting, future work

could focus on examining social aspects of recovery (24, 44, 45) and cross-disciplinary family research (46, 47). Inclusion of these contexts would broaden our focus beyond the current biomedical paradigm.

The majority of representatives were from the United States. The meeting therefore addressed issues within this U.S. legislative, funding and practice context. The principles of identifying, treating, and supporting patients and families during recovery from a critical illness are nevertheless global (41, 43, 48, 49). We do, however, acknowledge continuing debate regarding the benefits and limitations of promoting a clinical syndrome such as PICS, with such a broad constellation of signs and symptoms (50), that individual patients may not universally exhibit during their recovery.

We also note that our existing evidence based on the true prevalence rates of these postillness morbidities is imperfect and influenced by limitations in earlier study designs and methods. These previous limitations with sample sizes, enrollment rates, and recruitment bias, for example, are however improving with larger prospective cohort studies (51–53) now providing more accurate baseline and outcome measures.

Although this article reports only the discussion and outcomes from our 2-day meeting, ongoing work by meeting participants and others continues to advance the field.

## CONCLUSIONS

With increased survivorship from a critical illness, PICS is a growing public health issue. Increased public awareness about PICS and the risk of developing physical, cognitive, and mental health impairments is an important consideration and responsibility for healthcare professionals. Similarly, health professionals from a range of disciplines who care for ICU survivors across the recovery continuum require additional information, education, and resources to enable optimal treatment and support for individuals with PICS. This report provides an overview of our current understanding of PICS and also outlines an early action plan based on this SCCM meeting and collaborations with interdisciplinary partner organizations.

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