Reaching agreement on HOW to measure

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What & how have we measured in the past?

SCOPING REVIEW

Turnbull AE, Rabiee A, Davis WE, et al.
Crit Care Med 2016; 44:1267–1277

Outcome Measurement in ICU Survivorship Research From 1970 to 2013: A Scoping Review of 425 Publications

Alison E. Turnbull, DVM, MPH, PhD[1–3]; Anahita Rabiee, MD[1,2]; Wesley E. Davis, BA[1,2]; Mohamed Farhan Nasser, MBBS[1]; Venkat Reddy Venna, MBBS[1]; Rohini Lolitha, MBBS[1]; Ramona O. Hopkins, PhD[4–6]; O. Joseph Bienvenu, MD, PhD[1,7]; Karen A. Robinson, MSc, PhD[3,8,9]; Dale M. Needham, FCPA, MD, PhD[1,2,10]

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All authors contributed to the conception and/or design of this study. Dr. Turnbull, Dr. Rabiee, Mr. Davis, Mr. Nasser, Mr. Venna, Ms. Lolitha, Dr. Robinson, and Dr. Needham contributed to the acquisition of data. All authors contributed to the analysis and interpretation of the data. Dr. Turnbull drafted the article, and all authors critically revised it for important intellectual content and approved the final version to be submitted.

Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's website (http://journals.lww.com/ccmjournal).

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Objectives: To evaluate the study designs and measurement instruments used to assess physical, cognitive, mental health, and quality of life outcomes of survivors of critical illness over more than 40 years old as a first step toward developing a core outcome set of measures for future trials to improve outcomes in ICU survivors.

Design: Scoping review.

Setting: Published articles that included greater than or equal to one postdischarge measure of a physical, cognitive, mental health, or quality of life outcome in more than or equal to 20 survivors of critical illness published between 1970 and 2013. Instruments were classified using the World Health Organization's International Classification of Functioning, Disability, and Health framework.

Subjects: ICU survivors.

Interventions: None.

Measurements and Main Results: We reviewed 15,464 abstracts, and identified 425 eligible articles, including 31 randomized trials (7%), 116 cross-sectional studies (27%), and 278 cohort studies (65%). Cohort studies had a median (interquartile range) sample size of 96 survivors (52–209), with 38% not fully reporting loss to follow-up. A total of 250 different measurement instruments were used in these 425 articles. Among eligible articles, 25 measured physical activity limitations (6%), 40 measured cognitive activity limitations (9%), 114 measured mental health impairment (27%), 196 measured participation restriction (46%), and 276 measured quality of life (65%).

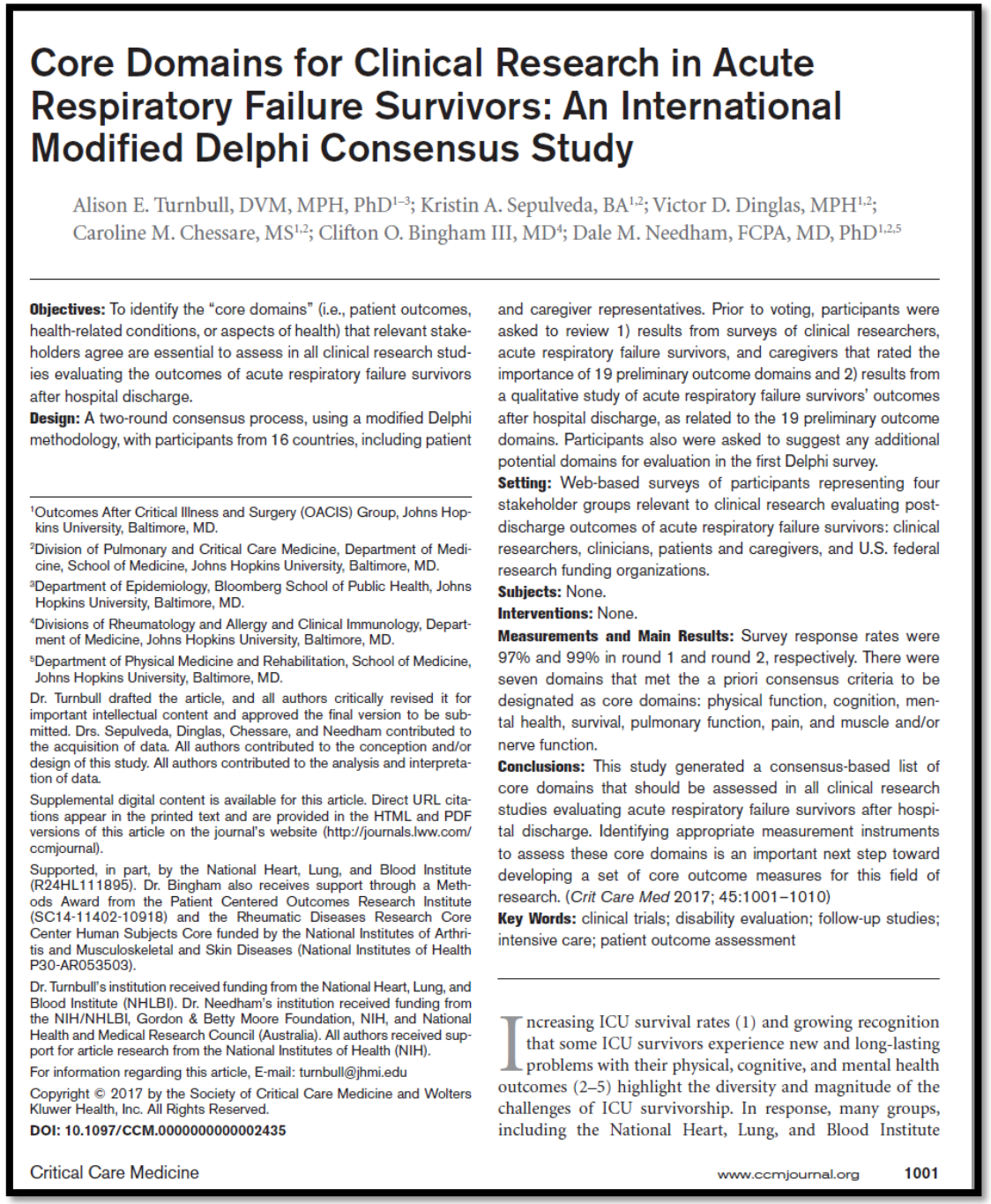
The Panel (N = 77)

- Acute Care for Africa Research and Training
- Asian Critical Care Trials Group
- Australian New Zealand Intensive Care Society Clinical Trials Group
- Brazilian Research in Intensive Care Network
- Canadian Critical Care Trials Group
- Chinese Critical Care Clinical Trials Group
- European Society of Intensive Care Medicine Clinical Trials Group
- Hellenic Sepsis Study Group
- International Forum for Acute Care Trialists (InFACT)
- Intensive Care National Audit & Research Centre (UK)
- Intensive Care Society - Clinical Trials Group (UK)
- Italian Group for Evaluation of Interventions in Intensive Care
- Irish Critical Care Trials Group
- Latin American Critical Care Trials Investigators Network
- Latin American Sepsis Institute
- The Clinical Trials Network for the Prevention and Early Treatment of Acute Lung Injury (USA)
- Scandinavian Critical Care Trials Group
- Scottish Critical Care Trials Group
- SepNet Trials Group
- UK Critical Care Research Forum
- US Critical Illness and Injury Trials Group
- 9 authors of internationally-recognized ARF outcomes research
- 6 corresponding authors from published ICU survivorship research
- NIH - Agency for Healthcare Research and Quality
- NIH - National Institute on Aging
- NIH - National Institute of Child Health and Human Development
- National Library of Medicine
- 2 Patient/Family reps from Australia
- 2 Patient/Family reps from Canada
- 2 Patient/Family reps from the UK
- 13 Patient/Family reps from the US
- Australian College of Critical Care Nurses
- Australian New Zealand Intensive Care Society
- Australian Physiotherapy Association
- Canadian Association of Critical Care Nurses
- Canadian Critical Care Society
- Canadian Physiotherapy Association
- British Association of Critical Care Nurses
- Association of Chartered Physiotherapists in Respiratory Care (UK)
- Intensive Care Society (UK)
- American Association of Critical-Care Nurses
- American Physical Therapy Association
- American Occupational Therapy Association
- American Speech-Language-Hearing Association
- American College of Chest Physicians
- American Thoracic Society
- American Academy of Physical Medicine and Rehabilitation
- Association of Academic Physiatrists (USA)
- American College of Clinical Pharmacy
- Society of Critical Care Medicine

What to measure

CORE OUTCOME SET

Turnbull AE, Sepulveda KA, Dinglas VD, et al.
Crit Care Med 2017; 45:1001–1010



Core Domains for Clinical Research in Acute Respiratory Failure Survivors: An International Modified Delphi Consensus Study

Alison E. Turnbull, DVM, MPH, PhD[1–3]; Kristin A. Sepulveda, BA[1,2]; Victor D. Dinglas, MPH[1,2]; Caroline M. Chessare, MS[1,2]; Clifton O. Bingham III, MD[4]; Dale M. Needham, FCPA, MD, PhD[1,2,5]

Objectives: To identify the "core domains" (i.e., patient outcomes, health-related conditions, or aspects of health) that relevant stakeholders agree are essential to assess in all clinical research studies evaluating the outcomes of acute respiratory failure survivors after hospital discharge.

Design: A two-round consensus process, using a modified Delphi methodology, with participants from 16 countries, including patient and caregiver representatives. Prior to voting, participants were asked to review 1) results from surveys of clinical researchers, acute respiratory failure survivors, and caregivers that rated the importance of 19 preliminary outcome domains and 2) results from a qualitative study of acute respiratory failure survivors' outcomes after hospital discharge, as related to the 19 preliminary outcome domains. Participants also were asked to suggest any additional potential domains for evaluation in the first Delphi survey.

Setting: Web-based surveys of participants representing four stakeholder groups relevant to clinical research evaluating post-discharge outcomes of acute respiratory failure survivors: clinical researchers, clinicians, patients and caregivers, and U.S. federal research funding organizations.

Subjects: None.

Interventions: None.

Measurements and Main Results: Survey response rates were 97% and 99% in round 1 and round 2, respectively. There were seven domains that met the a priori consensus criteria to be designated as core domains: physical function, cognition, mental health, survival, pulmonary function, pain, and muscle and/or nerve function.

Conclusions: This study generated a consensus-based list of core domains that should be assessed in all clinical research studies evaluating acute respiratory failure survivors after hospital discharge. Identifying appropriate measurement instruments to assess these core domains is an important next step toward developing a set of core outcome measures for this field of research. (*Crit Care Med* 2017; 45:1001–1010)

Key Words: clinical trials; disability evaluation; follow-up studies; intensive care; patient outcome assessment

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Dr. Turnbull drafted the article, and all authors critically revised it for important intellectual content and approved the final version to be submitted. Drs. Sepulveda, Dinglas, Chessare, and Needham contributed to the acquisition of data. All authors contributed to the conception and/or design of this study. All authors contributed to the analysis and interpretation of data.

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Dr. Turnbull's institution received funding from the National Heart, Lung, and Blood Institute (NHLBI). Dr. Needham's institution received funding from the NIH/NHLBI, Gordon & Betty Moore Foundation, NIH, and National Health and Medical Research Council (Australia). All authors received support for article research from the National Institutes of Health (NIH).

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Increasing ICU survival rates (1) and growing recognition that some ICU survivors experience new and long-lasting problems with their physical, cognitive, and mental health outcomes (2–5) highlight the diversity and magnitude of the challenges of ICU survivorship. In response, many groups, including the National Heart, Lung, and Blood Institute

HOW should researchers measure the outcomes in our COS?

How well have candidate instruments been evaluated?

SYSTEMATIC REVIEW

Robinson KA, Davis WE, Dinglas VD, et al.
J Clin Epidemiol 2017; 82:37–46

COSMIN = Consensus-based Standards for the selection of health Measurement Instruments

ELSEVIER

CrossMark

Journal of Clinical Epidemiology 82 (2017) 37–46

Journal of Clinical Epidemiology

A systematic review finds limited data on measurement properties of instruments measuring outcomes in adult intensive care unit survivors

Karen A. Robinson[a,*], Wesley E. Davis[b,c], Victor D. Dinglas[b,c], Pedro A. Mendez-Tellez[c,d], Anahita Rabiee[b,c], Vineeth Sukrithan[b,c], Ramakrishna Yalamanchilli[b,c], Alison E. Turnbull[b,c,e], Dale M. Needham[b,c,f]

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Abstract

Background and Objective: There is a growing number of studies evaluating the physical, cognitive, mental health, and health-related quality of life (HRQOL) outcomes of adults surviving critical illness. However, there is little consensus on the most appropriate instruments to measure these outcomes. To inform the development of such consensus, we conducted a systematic review of the performance characteristics of instruments measuring physical, cognitive, mental health, and HRQOL outcomes in adult intensive care unit (ICU) survivors.

Methods: We searched PubMed, Embase, PsycInfo, Cumulative Index of Nursing and Allied Health Literature, and The Cochrane Library in March 2015. We also conducted manual searches of reference lists of eligible studies and relevant review articles. Two people independently selected studies, completed data abstraction, and assessed the quality of eligible studies using the COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) initiative checklist.

Results: We identified 20 studies which explicitly evaluated measurement properties for 21 different instruments assessing outcomes in ICU survivors. Eleven of the instruments assessed quality of life, with few instruments assessing other domains. Of the nine measurement properties evaluated on the COSMIN checklist, six were assessed in < 10% of the evaluations. Overall quality of eligible studies was generally poor to fair based on the COSMIN checklist.

Conclusions: Although an increasing number of studies measure physical, cognitive, mental health, and HRQOL outcomes in adult ICU survivors, data on the measurement properties of such instruments are sparse and generally of poor to fair quality. Empirical analyses evaluating the performance of instruments in adult ICU survivors are needed to advance research in this field.

Keywords: Outcome measures; Critical care survivors; Systematic review

1. Introduction

With the aging population leading to increased demand for critical care services, and with improving short-term mortality in the intensive care unit (ICU), there is a growing number of survivors of critical illness [1,2]. Frequently such survivors experience significant challenges in their physical, cognitive, mental health, and quality of life (QOL) outcomes lasting long after hospital discharge [3]. Consequently, there is a growing number of studies evaluating postdischarge outcomes in adult ICU survivors.

More than 160 different outcome measures were identified in studies of adult ICU survivors in a 1998 systematic review [4,5]. This systematic review reported on the validity,

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http://dx.doi.org/10.1016/j.jclinepi.2016.08.014
0895-4356/

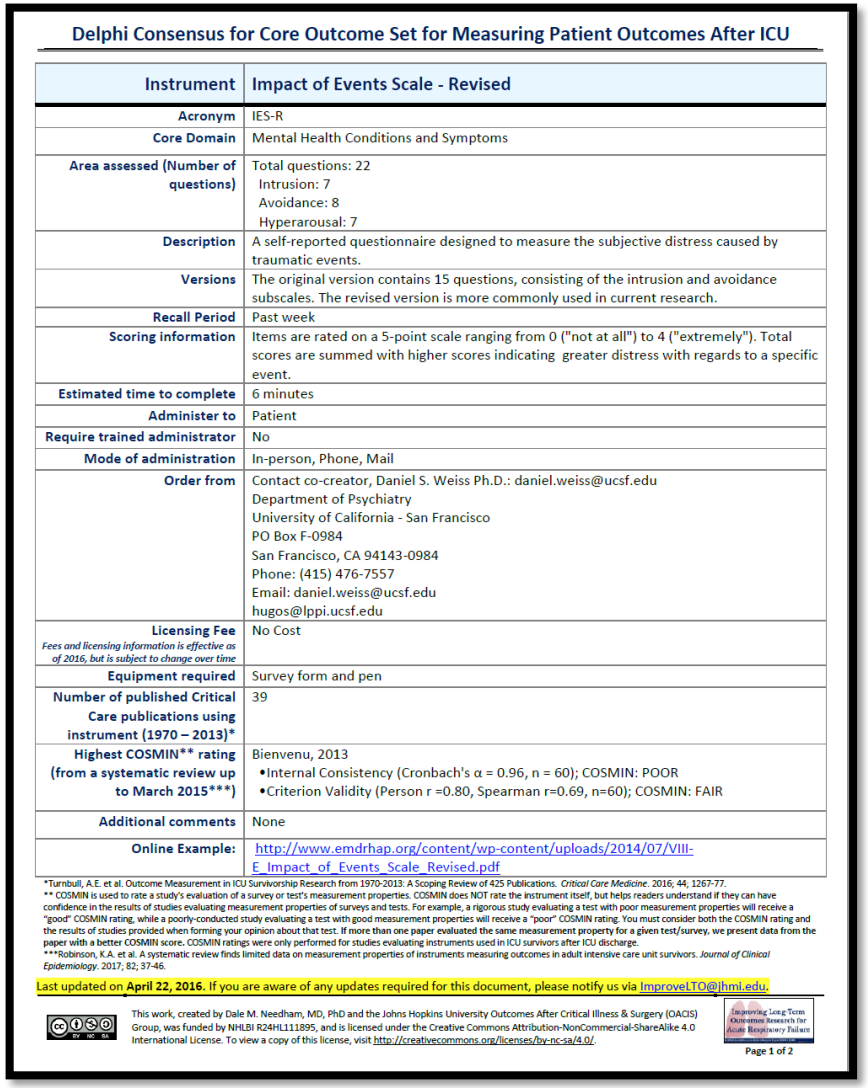
NEW valuations to inform voting

NEW PSYCHOMETRIC ANALYSES

1. Hospital Anxiety & Depression Scale (HADS): Internal consistency (*J Crit Care*. 2015; 30:793-8)
2. Minimal Important Difference of HADS & IES-R: (*Gen Hosp Psychiatry*. 2016;42:32-5)
3. SF-36 Mental Health domain correlation with psychiatric symptoms (*Ann ATS*. 2016;13:1343-50)
4. Impact of Event Scale–Revised (IES-R): Criterion validity (*Chest*. 2013;144:24-31)
5. 6-Minute Walk Test: validity, responsiveness; MID (Chest. 2015;147:1316-26)
6. 4-Meter Gait Speed: validity, responsive, reliability; MID (Crit Care Med. 2016; 44:859-68)
7. Physical performance-based measures vs. PRO (Thorax. 2017;72 884-892)
8. Dual energy X-ray absorptiometry body composition (Eur J Clin Nutr. 2018;72:613-617 and Crit Care Med. 2018;46:1238-1246)

Outcome Cards

5 most common measurement instruments per outcome from scoping review



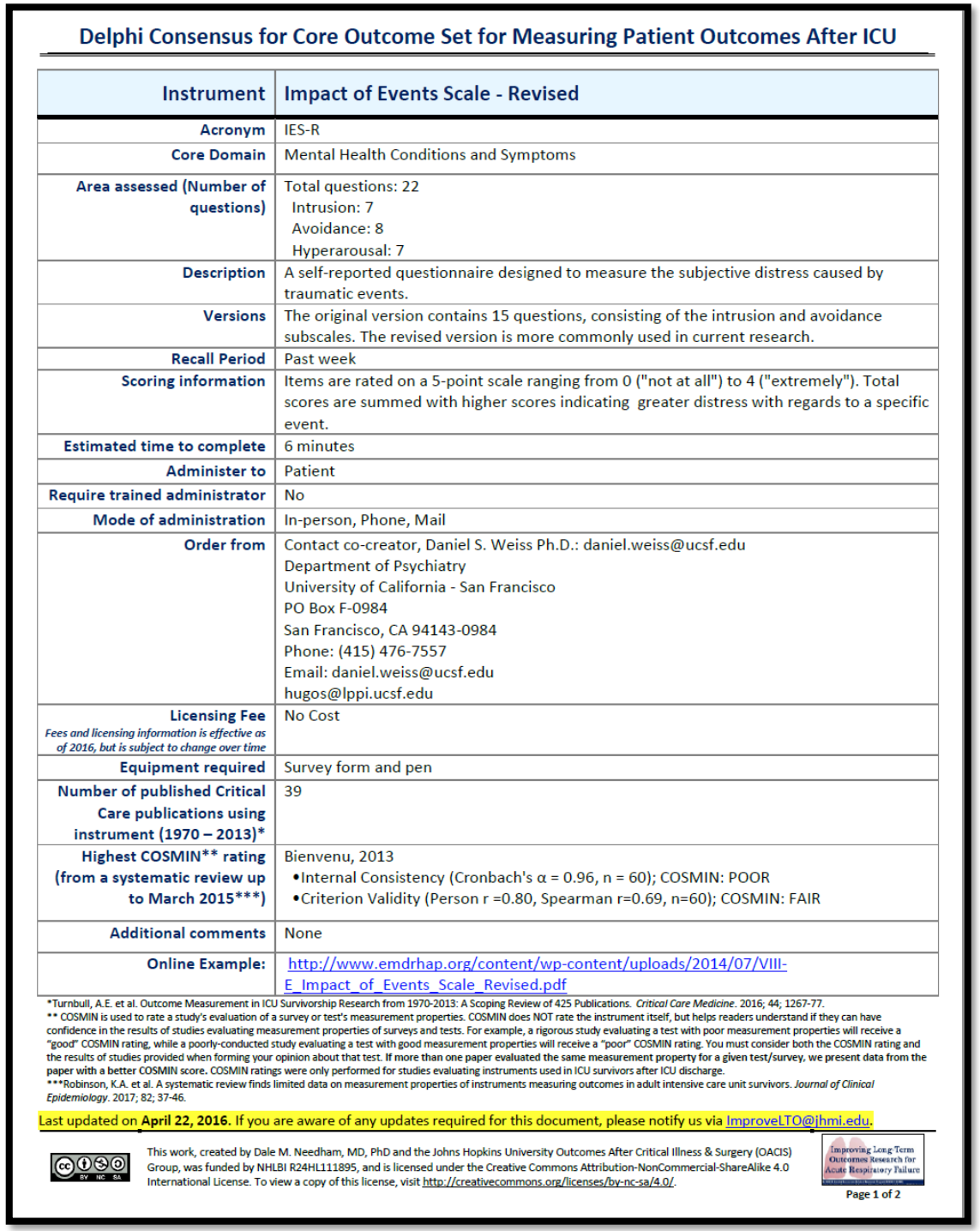
Delphi Consensus for Core Outcome Set for Measuring Patient Outcomes After ICU

Instrument	Impact of Events Scale - Revised
Acronym	IES-R
Core Domain	Mental Health Conditions and Symptoms
Area assessed (Number of questions)	Total questions: 22 Intrusion: 7 Avoidance: 8 Hyperarousal: 7
Description	A self-reported questionnaire designed to measure the subjective distress caused by traumatic events.
Versions	The original version contains 15 questions, consisting of the intrusion and avoidance subscales. The revised version is more commonly used in current research.
Recall Period	Past week
Scoring information	Items are rated on a 5-point scale ranging from 0 ("not at all") to 4 ("extremely"). Total scores are summed with higher scores indicating greater distress with regards to a specific event.
Estimated time to complete	6 minutes
Administer to	Patient
Require trained administrator	No
Mode of administration	In-person, Phone, Mail
Order from	Contact co-creator, Daniel S. Weiss Ph.D.: daniel.weiss@ucsf.edu Department of Psychiatry University of California - San Francisco PO Box F-0984 San Francisco, CA 94143-0984 Phone: (415) 476-7557 Email: daniel.weiss@ucsf.edu hugos@lppi.ucsf.edu
Licensing Fee *Fees and licensing information is effective as of 2016, but is subject to change over time*	No Cost
Equipment required	Survey form and pen
Number of published Critical Care publications using instrument (1970 – 2013)*	39
Highest COSMIN** rating (from a systematic review up to March 2015***)	Bienvenu, 2013 •Internal Consistency (Cronbach's α = 0.96, n = 60); COSMIN: POOR •Criterion Validity (Person r =0.80, Spearman r=0.69, n=60); COSMIN: FAIR
Additional comments	None
Online Example:	http://www.emdrhap.org/content/wp-content/uploads/2014/07/VIII-E_Impact_of_Events_Scale_Revised.pdf

*Turnbull, A.E. et al. Outcome Measurement in ICU Survivorship Research from 1970-2013: A Scoping Review of 425 Publications. *Critical Care Medicine*. 2016; 44, 1267-77.
** COSMIN is used to rate a study's evaluation of a survey or test's measurement properties. COSMIN does NOT rate the instrument itself, but helps readers understand if they can have confidence in the results of studies evaluating measurement properties of surveys and tests. For example, a rigorous study evaluating a test with poor measurement properties will receive a "good" COSMIN rating, while a poorly-conducted study evaluating a test with good measurement properties will receive a "poor" COSMIN rating. You must consider both the COSMIN rating and the results of studies provided when forming your opinion about that test. **If more than one paper evaluated the same measurement property for a given test/survey, we present data from the paper with a better COSMIN score.** COSMIN ratings were only performed for studies evaluating instruments used in ICU survivors after ICU discharge.
***Robinson, K.A. et al. A systematic review finds limited data on measurement properties of instruments measuring outcomes in adult intensive care unit survivors. *Journal of Clinical Epidemiology*. 2017; 82; 37-46.

Last updated on **April 22, 2016**. If you are aware of any updates required for this document, please notify us via ImproveLTO@jhmi.edu.

- Number of questions
- Minutes required for completion
- Licensing and cost
- Scoring system
- Administration (phone, mail, etc)
- Web link to questions
- Number of times used in this population since 1975
- COSMIN rating



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Description	A self-reported questionnaire designed to measure the subjective distress caused by traumatic events.
Versions	The original version contains 15 questions, consisting of the intrusion and avoidance subscales. The revised version is more commonly used in current research.
Recall Period	Past week
Scoring information	Items are rated on a 5-point scale ranging from 0 ("not at all") to 4 ("extremely"). Total scores are summed with higher scores indicating greater distress with regards to a specific event.
Estimated time to complete	6 minutes
Administer to	Patient
Require trained administrator	No
Mode of administration	In-person, Phone, Mail
Order from	Contact co-creator, Daniel S. Weiss Ph.D.: daniel.weiss@ucsf.edu Department of Psychiatry University of California - San Francisco PO Box F-0984 San Francisco, CA 94143-0984 Phone: (415) 476-7557 Email: daniel.weiss@ucsf.edu hugos@lppi.ucsf.edu
Licensing Fee *Fees and licensing information is effective as of 2016, but is subject to change over time*	No Cost
Equipment required	Survey form and pen
Number of published Critical Care publications using instrument (1970 – 2013)*	39
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Additional comments	None
Online Example:	http://www.emdrhap.org/content/wp-content/uploads/2014/07/VIII-E_Impact_of_Events_Scale_Revised.pdf

*Turnbull, A.E. et al. Outcome Measurement in ICU Survivorship Research from 1970-2013: A Scoping Review of 425 Publications. *Critical Care Medicine*. 2016; 44; 1267-77.
** COSMIN is used to rate a study's evaluation of a survey or test's measurement properties. COSMIN does NOT rate the instrument itself, but helps readers understand if they can have confidence in the results of studies evaluating measurement properties of surveys and tests. For example, a rigorous study evaluating a test with poor measurement properties will receive a "good" COSMIN rating, while a poorly-conducted study evaluating a test with good measurement properties will receive a "poor" COSMIN rating. You must consider both the COSMIN rating and the results of studies provided when forming your opinion about that test. If more than one paper evaluated the same measurement property for a given test/survey, we present data from the paper with a better COSMIN score. COSMIN ratings were only performed for studies evaluating instruments used in ICU survivors after ICU discharge.
***Robinson, K.A. et al. A systematic review finds limited data on measurement properties of instruments measuring outcomes in adult intensive care unit survivors. *Journal of Clinical Epidemiology*. 2017; 82; 37-46.

Last updated on **April 22, 2016.** If you are aware of any updates required for this document, please notify us via ImproveLTO@jhmi.edu.

Delphi Manager content - Round 1

The webpage for each outcome contained:

- Link to the scoping review
- Definition of a Core Outcome Measure Set!
- Inclusions/Exclusion criteria
- Links to measurement card for each measure under consideration
- Space to suggest additional measures
- Voting

Delphi Manager content - Round 2

The webpage for each outcome contained:

- Link to the scoping review
- Inclusions/Exclusion criteria
- Links to measurement card for each measure under consideration
- Results of Round 1 voting
- Link to result of Round 1 voting by stakeholder group
- Anonymized comments from Round
- Voting

COMET INITIATIVE DelphiManager

Logout

Muscle and/or Nerve Function

Please do not use the browser's back button.

You have answered: 84 out of 84 outcomes **Page 5 of 17**

Below are results of the prior survey for the Core Domain, *Muscle and/or Nerve Function*.

Based on the last survey, **NO** measure has reached consensus yet for inclusion in a Core Outcome Set.

Please review the criteria for consensus and the prior survey results below. After reviewing this information, please decide if you will retain or revise your prior survey response. **Keep in mind that the goal is to reach consensus on a measure for this Core Domain.**

Criteria for consensus: a measure will be included in the Core Outcome Set if it meets both criteria among panel members who are able to score the measure:

1. at least 70% of ALL panel members rate the measure greater than 7 out of 9 (i.e., considered "critical" for inclusion), and

2. no more than 15% of ALL panel members rate the measure less than 3 out of 9 (i.e., considered "not important" for inclusion).

The table below summarize responses from the last survey. Here is an explanation of the color coding used within the tables:

Greater than 15% rated "Not Important" for inclusion; the measure **would NOT be included** in Core Outcomes Set
Between 10-15% rated "Not Important" for inclusion; the measure is **close to NOT being included**

If no more than 15% of responders rated "Not Important" for inclusion AND
At least 70% rated "Critical" for inclusion; the measure **would be included** in Core Outcomes Set
Between 60-69% scored "Critical" for inclusion; the measure is **close to being included**

	Results for ALL stakeholders*	
Muscle and/or Nerve Function	**Not Important for Inclusion**	**Critical for Inclusion**
Electromyography/Nerve Conduction Studies	28%	19%
Manual Muscle Test	10%	46%
Grip Strength	4%	42%

**Percentages calculated among those who were able to respond. Out of 75 panel members, the number unable to respond are: Electromyography/Nerve Conduction Studies (5), Manual Muscle Test (3), Grip Strength (5)*

Please also review the results broken down by **Stakeholder Group**.

The outcome measures, below, were selected based on prior use in survivors of critical illness [**LINK TO SCOPING REVIEW**] plus NEWLY ADDED measures from panel members' input on the previous survey.

Please review the resources below for specific information on each measure. Each resource includes standardized data for the coinciding measure; please note that some of the resources have hyperlinks offering more information and demonstration videos (if the hyperlink does not automatically open to a new webpage, please manually copy the hyperlink into your internet browser). After reviewing the resources, rate the appropriateness of each outcome measure, below, for inclusion in a Core Outcomes Set. Your prior response is highlighted in yellow. The NEWLY ADDED measures do not have highlighting within the response options.

Resources: Electromyography/Nerve Conduction Studies | Grip Strength | Hand-Held Dynamometry | Manual Muscle Test

These resources are also available within the pdf, called "Measure Cards", attached to the email invitation to this survey.

Please do not feel compelled to answer every question. If you do not feel comfortable rating a measure (e.g., you don't have sufficient information or expertise to make a decision), please select "Unable to Score".

If you feel unable to provide a score based on your experience, please select 'unable to score'.

In the table below, your score from the previous survey is highlighted in yellow along with the percentage of participants who provided scores for that row in the prior survey.

Outcome		Not important			Important but not critical			Critical			
	Number of people scoring this outcome	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*Unable to score*
Muscle and/or Nerve Function											
Electromyography/Nerve Conduction Studies	*67*	*6%* ○	*9%* ○	*13%* ○	*21%* ○	*12%* ○	*19%* ○	*12%* ○	*4%* ○	*3%* ○	◉
Grip Strength	*67*	*1%* ○	*1%* ○	*1%* ○	*7%* ○	*21%* ○	*25%* ○	*22%* ○	*10%* ○	*9%* ○	◉
Manual Muscle Test	*69*	*1%* ○	*4%* ○	*4%* ○	*6%* ○	*12%* ○	*26%* ○	*22%* ○	*13%* ○	*12%* ○	◉
NEW (suggested in the prior survey): Hand Held Dynamometry	*0*	*0%* ○	*0%* ○	*0%* ○	*0%* ○	*0%* ○	*0%* ○	*0%* ○	*0%* ○	*0%* ○	◉
Row intentionally left blank; please mark "Unable to Score"	*0*	*0%* ○	*0%* ○	*0%* ○	*0%* ○	*0%* ○	*0%* ○	*0%* ○	*0%* ○	*0%* ○	◉

Please note: *You will only be able to save/move to the next page if you have answered* **ALL** *the questions on this page.*

Save and Exit

Goto Page 15 ▾ Or Next Page

How to measure

CORE OUTCOME MEASUREMENT SET (COMS)

Needham DM, Sepulveda KA, Dinglas VD, et al.
Am J Respir Crit Care Med 2017; 196:1122–1130

ORIGINAL ARTICLE

Core Outcome Measures for Clinical Research in Acute Respiratory Failure Survivors

An International Modified Delphi Consensus Study

Dale M. Needham[1,2,3], Kristin A. Sepulveda[1,2], Victor D. Dinglas[1,2], Caroline M. Chessare[1,2], Lisa Aronson Friedman[1,2], Clifton O. Bingham III[4,5], and Alison E. Turnbull[1,2,6]

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Abstract

Rationale: Research evaluating acute respiratory failure (ARF) survivors' outcomes after hospital discharge has substantial heterogeneity in terms of the measurement instruments used, creating barriers to synthesizing study data.

Objectives: To identify a minimum set of core outcome measures that are essential to include in all clinical research studies evaluating ARF survivors after discharge.

Methods: We conducted a three-round modified Delphi consensus process with 77 participants (47% female, 55% outside the United States), including clinical researchers from more than 16 countries across six continents, patients/caregivers, clinicians, and research funders. Participants reviewed standardized information on measure instruments for seven consensus-derived outcomes plus one recommended outcome.

Measurements and Main Results: Response rates were 91 to 97% across the three rounds. Among 75 measurement instruments evaluated, the following met *a priori* consensus criteria: EQ-5D and 36-item Short Form Health Survey version 2 (optional) for the "satisfaction with life and personal enjoyment" and "pain" outcomes, and both the Hospital Anxiety and Depression Scale and the Impact of Events Scale–Revised for the "mental health" outcome. No measures reached consensus for the following outcomes: cognition, muscle and/or nerve function, physical function, and pulmonary function. All measures considered for pulmonary function met consensus criteria for exclusion. The following measures did not reach the threshold for consensus but achieved the highest scores for their respective outcomes: the Montreal Cognitive Assessment (cognition), manual muscle testing and handgrip dynamometry (muscle and/or nerve function), and 6-minute-walk test (physical function).

Conclusions: This Core Outcome Measurement Set is recommended for use in all clinical research evaluating ARF survivors after hospital discharge. In the future, researchers should evaluate measures for outcomes not reaching consensus.

Keywords: patient outcome assessment; follow-up studies; Core Outcome Measurement Set; clinical trials; intensive care

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Author Contributions: D.M.N.: had full access to all data in the study, takes full responsibility for the integrity of the data and the accuracy of the data analysis, and supervised the study; K.A.S., C.M.C., V.D.D., and D.M.N.: contributed to the acquisition of data; L.A.F.: conducted the statistical analysis; D.M.N., K.A.S., and A.E.T.: drafted the article; all authors: developed the study concept and design, interpreted the data, provided critical revisions for important intellectual content, and read and approved the final manuscript.

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Feedback from panelists

The time required for participation was appropriate: 91%

ELSEVIER

Journal of Clinical Epidemiology 102 (2018) 99–106

Journal of Clinical Epidemiology

ORIGINAL ARTICLE

A survey of Delphi panelists after core outcome set development revealed positive feedback and methods to facilitate panel member participation

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Conclusion: This international Delphi panel, including >20% patients/caregivers, favorably reported on feasibility of the methodology. Providing all panelists pertinent information/reminders about the project's objective at each voting round is important to informed decision making across all stakeholder groups.

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Not bothered by reminders to participate: 96%

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How informed were their votes?

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A study reported 'poor' reliability of a muscle strength measure, but the study had an 'excellent' COSMIN rating.

COSMIN is used to rate a study's evaluation of the measurement properties of the instrument. COSMIN does not rate the instrument itself but helps readers understand if they can have confidence in the results of studies evaluating measurement properties of surveys and test.

Please select the statement that is TRUE from the choices below:

84% correct

73% of pt/family

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A hypothetical core outcome set has seven core domains, with one measurement tool recommended for each domain.

For researched designing new studies in the this field, what is the minimum number of measurement tools that should be used in their study?"

29% correct

Only 38% of researchers

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Conclusions

- Set expectations about participation
- Reminders → High response rate
- Re-explain important concepts on each webpage
- You don’t have to reach agreement on a measure for every outcome

Thank you

www.improveLTO.com

www.aeturnbull.org

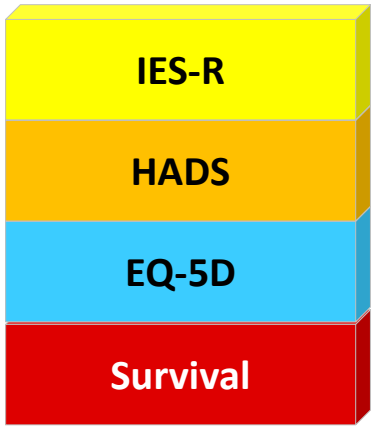
turnbull@jhmi.edu

EXTRA SLIDES

Improving Long-Term Outcomes Research for Acute Respiratory Failure

An NHLBI-funded Resource-Related Research Project (R24HL111895)
Johns Hopkins University's Outcomes After Critical Illness and Surgery (OACIS) Group

Acceptable Configurations of the Core Outcome Measurement Set (COMS) for Clinical Research in Acute Respiratory Failure Survivors



All patient-reported survey-based instruments that can be administered by phone

Total Number of Questions	42
Estimated Time to Complete (Mins)	12
Estimated Cost per Visit (as of June 2017)	$1.50

Am J Resp Crit Care Med. **2017;196:1122-1130.**

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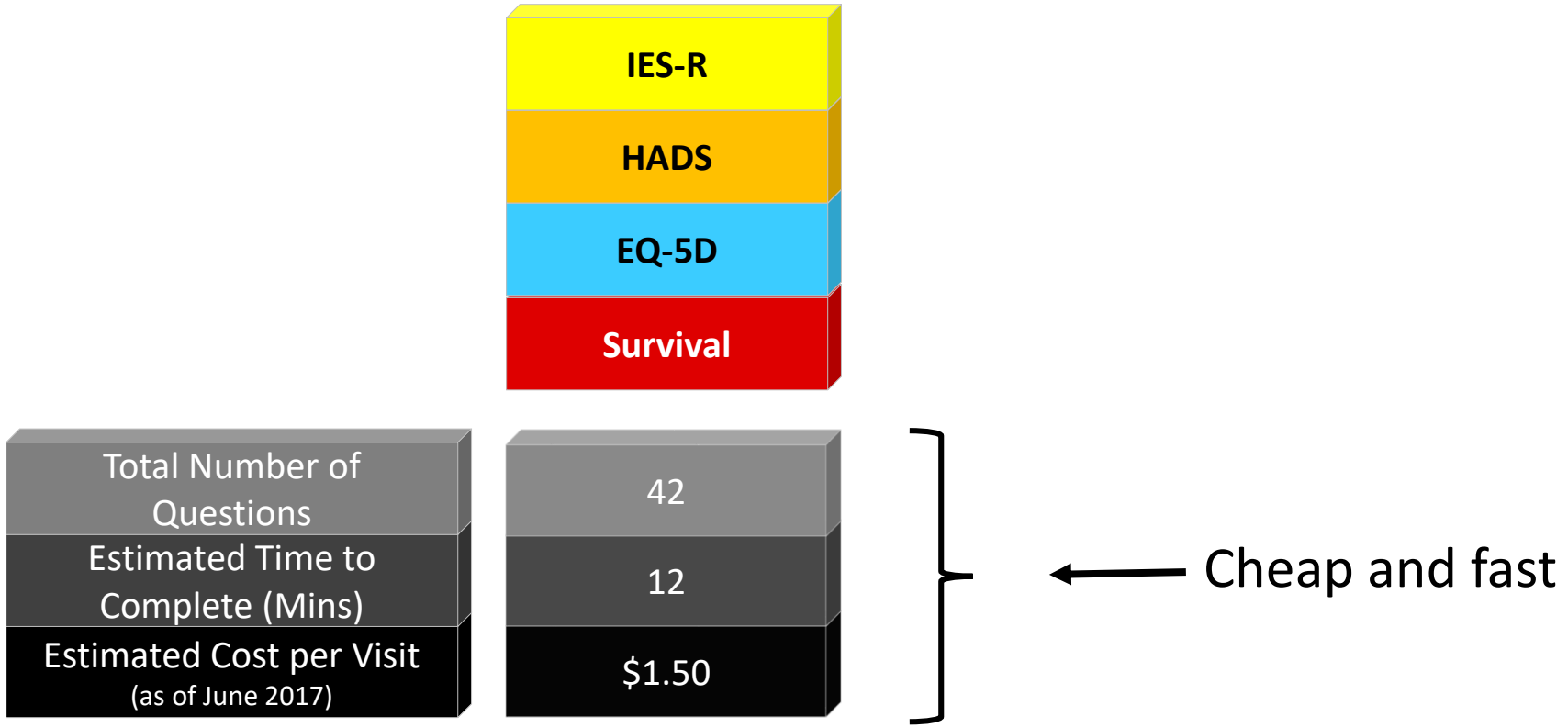

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Perfectly good car

IES-R

HADS

EQ-5D

Survival

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Nice if you can afford it

	IES-R	IES-R
	HADS	HADS
	EQ-5D	EQ-5D
	Survival	Survival
Total Number of Questions	42	91
Estimated Time to Complete (Mins)	12	26
Estimated Cost per Visit (as of June 2017)	$1.50	≥ $3.00

SF-36 v2

MoCA-BLIND

+

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≥ 15 Languages Available for Core Outcome Measurement Set (COMS) for Clinical Research in Acute Respiratory Failure Survivors *(as of January 2018)*

Language	EQ-5D	HADS	IES-R	SF-36 V2	MoCA-BLIND
Chinese	✓	✓	✓	✓	✓
Dutch	✓	✓	✓	✓	✓
English	✓	✓	✓	✓	✓
French	✓	✓	✓	✓	✓
German	✓	✓	✓	✓	✓
Greek	✓	✓	✓	✓	✓
Hebrew	✓	✓	✓	✓	✓
Japanese	✓	✓	✓	✓	✓
Korean	✓	✓	✓	✓	✓
Lithuanian	✓	✓	✓	✓	✓
Norwegian	✓	✓	✓	✓	✓
Russian	✓	✓	✓	✓	✓
Spanish	✓	✓	✓	✓	✓
Swedish	✓	✓	✓	✓	✓
Turkish	✓	✓	✓	✓	✓
Farsi	✓	✓	✓		