Reaching agreement on **HOW** to measure

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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
What & how have we measured in the past?

SCOPING REVIEW

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
- National Library of Medicine
- 2 Patient/Family reps from the US
- 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

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
NEW valuations to inform voting

NEW PSYCHOMETRIC ANALYSES


3. SF-36 Mental Health domain correlation with psychiatric symptoms *(Ann ATS. 2016;13:1343-50)*


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)*

Outcome Cards

5 most common measurement instruments per outcome from scoping review
• 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
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
**Muscle and/or Nerve Function**

*Please do not use the browser's back button.*

You have answered: 84 out of 84 outcomes

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 Outcome Set.
- Between 20-45% rated "Not Important" for inclusion; the measure is close to NOT being included.
- If no more than 1% of respondents rated "Not Important" for inclusion AND:
- At least 70% rated "Critical" for inclusion; the measure should be included in Core Outcome Set.
- Between 0-69% scored "Critical" for inclusion; the measure is close to being included.

<table>
<thead>
<tr>
<th>Muscle and/or Nerve Function</th>
<th>Not Important for Inclusion</th>
<th>Critical for Inclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Electromyography/Nerve Conduction Studies</td>
<td>28%</td>
<td>10%</td>
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<tr>
<td>Manual Muscle Test</td>
<td>10%</td>
<td>40%</td>
</tr>
<tr>
<td>Grip Strength</td>
<td>4%</td>
<td>42%</td>
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</table>

*Percentages calculated among those who were able to respond. Out of 73 panel members, the number unable to respond are:
Electromyography/Nerve Conduction Studies (5), Manual Muscle Test (3), Grip Strength (3)*

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.

<table>
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<tr>
<th>Outcomes</th>
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<th>Important but not critical</th>
<th>Critical</th>
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<td>Number of people scoring the outcome</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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**Muscle and/or Nerve Function**

| Electromyography/Nerve Conduction Studies | 67 | 5% | 3% | 13% | 17% | 12% | 4% | 2% |
| Grip Strength | 57 | 1% | 1% | 7% | 21% | 22% | 10% | 6% |
| Manual Muscle Test | 59 | 1% | 4% | 4% | 6% | 12% | 22% | 13% |
| NEW (suggested in the prior survey): Hand Held Dynamometry | ? | 0% | 0% | 6% | 0% | 0% | 0% | 0% |
| NEW (suggested in the prior survey): Hand Held Dynamometry | ? | 0% | 0% | 6% | 0% | 0% | 0% | 0% |

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

CORE OUTCOME MEASUREMENT SET (COMS)

Feedback from panelists

The time required for participation was appropriate: 91%
Feedback from panelists

Not bothered by reminders to participate: 96%
How informed were their votes?
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
A hypothetical core outcome set has seven core domains, with one measurement tool recommended for each domain.

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

• Set expectations about participation

• Reminders $\rightarrow$ 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
Acceptable Configurations of the Core Outcome Measurement Set (COMS) for Clinical Research in Acute Respiratory Failure Survivors

- IES-R
- HADS
- EQ-5D
- Survival

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

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

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

Survival

EQ-5D

HADS

IES-R

Total Number of Questions

42

Estimated Time to Complete (Mins)

12

Estimated Cost per Visit

$1.50

(as of June 2017)

Perfectly good car

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

Total Number of Questions: 26
Estimated Time to Complete (Mins): 42
Estimated Cost per Visit (as of June 2017): $1.50

Nice if you can afford it

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