

## Core set of long-term outcome measures for studies of ICU survivors

The BACCN participated in a Delphi consensus process to create a core set of long-term outcome measures for studies of ICU survivors (panel member: *Catherine Plowright*).

This consensus work is now published  
The summary of results are as follows:

1. **Core Outcome Set (COS)** - see: <http://www.improvelto.com/coms/>

The panel **recommended** 8 core outcome domains:

1. *Survival*
2. *Satisfaction with Life and Personal Enjoyment (Health-related Quality of Life)*
3. *Mental health*
4. *Pain*
5. *Cognition*
6. *Physical function*
7. *Muscle and/or nerve function*
8. *Pulmonary function*

**Citation:** Turnbull AE, Sepulveda KA, Dinglas VD, Bingham CO, Needham DM. Core domains for clinical research in acute respiratory failure survivors: an international modified Delphi consensus study. *Critical Care Medicine*. 2017 Jun; 45(6):1001-1010. [PubMed](#)

2. **Core Outcome Measurement Set (COMS)** - see: <http://www.improvelto.com/coms/>

The following measurement instruments are recommended for the Core Outcomes from above:

1. *Satisfaction with Life and Personal Enjoyment (Health-related Quality of Life):* EQ-5D; Short Form-36 v2 (optional)
2. *Mental Health:* Hospital Anxiety & Depression Scale, and Impact of Events Scale-Revised (PTSD)
3. *Pain:* EQ-5D Pain Question
4. *Cognition:* Montreal Cognitive Assessment-Blind (MoCA-Blind; optional)

**Citation:** Needham DM, Sepulveda KA, Dinglas VD, Chessare CM, Friedman LA, Bingham III CO, Turnbull AE. Core outcome measures for clinical research in acute respiratory failure survivors: an international modified Delphi consensus study. *Am J Respir Crit Care Med*. 2017. ePub. [PubMed](#)

If you are planning a study that will evaluate patient outcomes after hospital discharge, please contact [improvelTO@jhmi.edu](mailto:improvelTO@jhmi.edu). They have a VERY brief survey to evaluate use of the COMS.

“Measure Cards” (also known as “Instrument Cards”) were a resource that were also provided during the Delphi process. All of these Cards (a total of 93 cards) are freely available, as a reference source, on our website ([www.improvelto.com/instruments/](http://www.improvelto.com/instruments/)). These Cards contains standardized information about the survey/test (e.g. estimated time to complete, licensing, frequency of use in prior research, psychometric properties, etc.).

Other resources available on their website include:

- (1) adaptable tools, templates, and manuals to maximize retention of research participants in post-discharge studies, including an interactive searchable database of >600 retention strategies; and

(2) a statistical tool to address truncation due to mortality when evaluating patients' functional outcomes in the setting of a competing risk of death.

**If you have any question, feel free to contact [improveLTO@jhmi.edu](mailto:improveLTO@jhmi.edu)**

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