



JOHNS HOPKINS
M E D I C I N E

Post-Intensive Care Syndrome (PICS)

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Mr. G.

ICU Stay per Medical Record

- 39 year old male
- PMH: Asthma, upper GI disease
 - No psychiatric Hx, no drug use
 - Gym 90 min/day
 - Work 55 hr/week; father of 4 children
- ICU admit: pneumonia with ARDS; **10 day LOS**
- On Floor x **6 day**: independent in ADLs by discharge
- **D/C to Home**: out-patient physiotherapy

Mr. G.

Self-Reported Outcomes

	Pre-ICU	6 mo.	12 mo.
Bench press	325 lbs	225 lbs	270 lbs
Jogging	3 miles	1 mile	2 miles
Gym workout	90 min	40 min	85 min
# of daily tasks	7 tasks	3 tasks	5 tasks
# productive hr/day	16 hour	8 hour	12 hour
Employment	53 hr/wk*	None	55 hrs/wk Lower work**

* Grocery store manager that required physical & cognitive effort

**Manager at Family Dollar

Mr. G.

First 6 months at home...

- **Cognition: difficult s-t memory & multi-tasking**
 - Completing son's simple school form was almost impossible
- **Distressing ICU memories - ICU “haunts” him**
- **Mood:**
 - “Always on edge” and frustrated/impatient
 - **Thinks about dying everyday**
 - Fears ARDS may return whenever he gets a cold
- **Distanced from others**

Mr. G.



Psychological Outcomes (**Validated surveys**)

	Pre-ALI	6 mo	12 mo
PTSD (IES-R; 0-4, Cut-off >1.5)	N/A	2.6	1.7
Anxiety (HAD; 0-21, Cut-off ≥8/11)	N/A	12	15
Depression (HAD; 0-21, Cut-off ≥8/11)	N/A	9	4
Fatigue (FACIT-IV; 0-100 higher better; cut-off 68)	59	51	62

Outline

1. **Post-Intensive Care Syndrome (PICS) term** *(from SCCM)*
2. **Highlight common post-ICU complications using systematic reviews**
 - Physical function
 - Psychiatric, Cognitive
 - QOL, Return to work

Concise Definitive Review Section Editor, Jonathan E. Sevransky, MD, MHS

Crit Care Med 2011 Vol. 39, No. 2

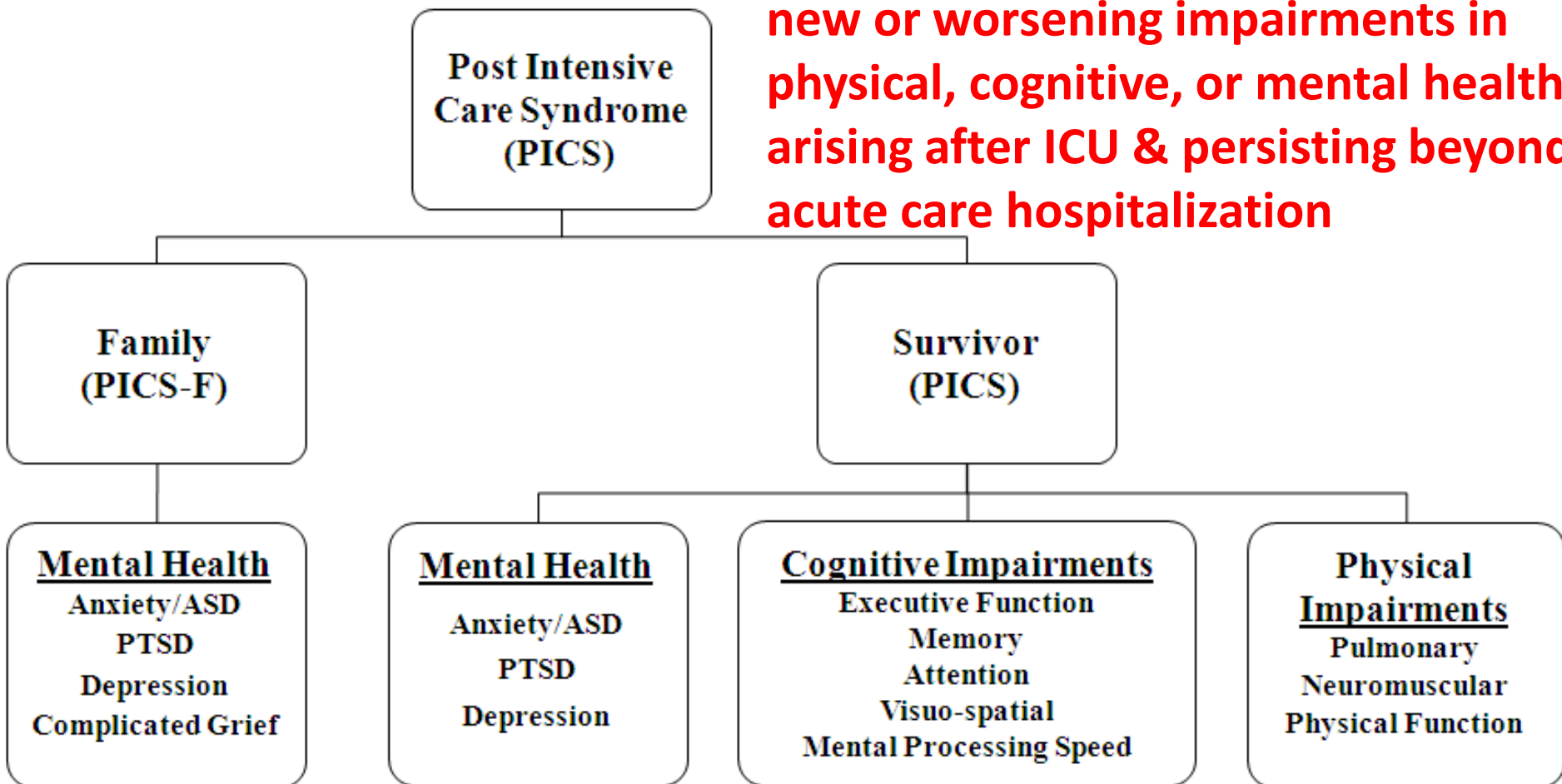
Long-term complications of critical care

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

(Crit Care Med 2012; 40:502–509)

Dale M. Needham, MD, PhD; Judy Davidson, DNP, RN; Henry Cohen, PharmD; Ramona O. Hopkins, PhD;

new or worsening impairments in physical, cognitive, or mental health arising after ICU & persisting beyond acute care hospitalization



Important Notes about Post-Intensive Care Syndrome (PICS)

Care Med 2012; 40:502–509)

- Created via **Society of Critical Care Medicine (SCCM)** multi-disciplinary int'l stakeholder conf. (**incl. patient/family**)
- Term applied to either a **survivor (PICS)** or **family (PICS-F)**
- **Created with following intentions:**
 - **synthesis of >20 years** of prior research on post-ICU outcomes
 - **increase awareness** in stakeholders (patient/family, clinicians & public)
 - Patients/families & clinicians not understand Post-ICU challenges
 - prompt out-patient **screening** for specific impairments after ICU
 - stimulate **investigation** into specific impairments after ICU
 - **no intention** for investigation of epidemiology of “PICS,” or interventions/trials for treatment of “PICS”

Source: @DrDaleNeedham (twitter)

Physical Function: IADL

- **IADL**: phone, shop, food prep, housekeeping, laundry, transport, meds, finances
- **~2/3 have impairments over 1-2 year follow-up**
 - ICU survivors vent for >48 hrs:
 - Impairment in >70% at 1-yr follow up
 - ARDS cohort over 2 years:
 - **NEW** impairment in 66% of cohort

Chelluri *CCM* 2004; 61-69; Boumendil *ICM* 2004; 647-654; Bienvenu *AJRCCM* 2011



Instrumental Activities of Daily Living after Critical Illness: A Systematic Review

Ann Am Thorac Soc Vol 14, No 8, pp 1332–1343, Aug 2017

Ramona O. Hopkins^{1,2,3,4}, Mary R. Suchyta⁵, Biren B. Kamdar⁶, Emily Darowski⁷, James C. Jackson^{8,9}, and Dale M. Needham¹⁰

Source: @DrDaleNeedham (twitter)

Six-Minute Walk Distance After Critical Illness: A Systematic Review and Meta-Analysis

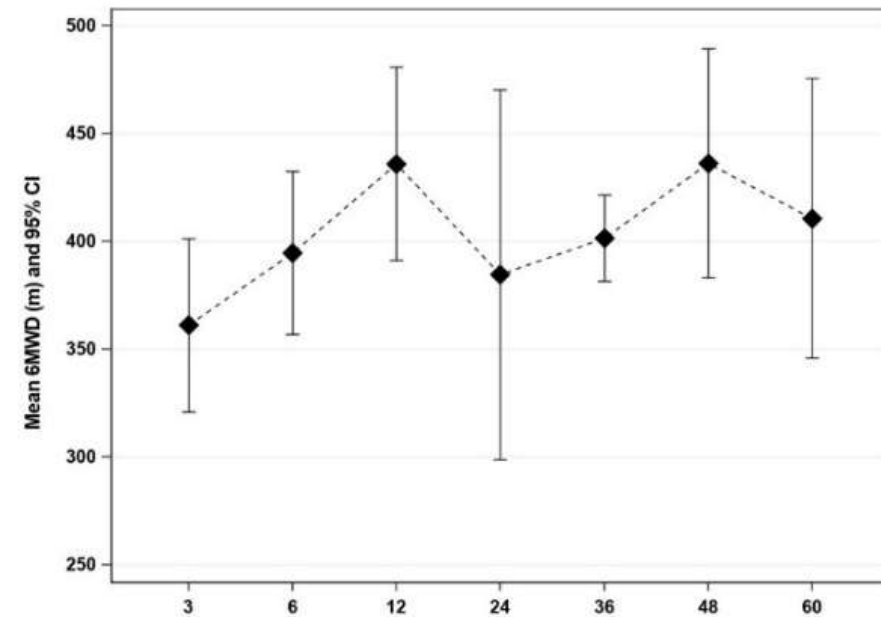
Selina M. Parry, PT, PhD¹ , Swaroopa R. Nalamalapu, MD², Krishidhar Nunna, MD³, Anahita Rabiee, MD⁴, Lisa Aronson Friedman, ScM^{5,6}, Elizabeth Colantuoni, PhD^{5,7}, Dale M. Needham, FCPA, MD, PhD^{5,6,8}, and Victor D. Dinglas, MPH^{5,6} 

Systematic review of 5 year follow-up

- 26 articles of 16 unique international cohorts

Main Results

- All timepoints below norms
- Large increase btwn 3 & 12 mo.



Mental Health

- **PTSD** pooled incidence (meta-analysis):
 - **~25% over 1 year** (range 17%-44%; IES meta-analysis, 6 studies)
32% & 10% by clinical interview (2 studies)
 - Symptoms up to 8 yrs after ARDS
- **Depression** pooled prevalence (meta-analysis):
 - **~30% over 1 year** (range: 4%-64%; general ICU, 38 studies)
 - **No improvement over 1st year**

PTSD: Parker et al *Critical Care Med* 2015
Depression: Rabiee et al *Critical Care Med* 2016

Source: @DrDaleNeedham (twitter)

Long-Term Cognitive Impairment after Critical Illness

N Engl J Med 2013;369:1306-16.

P.P. Pandharipande, T.D. Girard, J.C. Jackson, A. Morandi, J.L. Thompson,
B.T. Pun, N.E. Brummel, C.G. Hughes, E.E. Vasilevskis, A.K. Shintani,
K.G. Moons, S.K. Geevarghese, A. Canonico, R.O. Hopkins, G.R. Bernard,
R.S. Dittus, and E.W. Ely, for the BRAIN-ICU Study Investigators*

- **821 ICU pts w/ respiratory failure or shock**
- **~1/3 & 1/4 had cognitive scores at 1 year follow-up
c/w moderate TBI & mild Alzheimer's, respectively**
 - **Affected both older and younger pts**

Understanding patient outcomes after acute respiratory distress syndrome: identifying subtypes of physical, cognitive and mental health outcomes

Thorax 2017

Samuel M Brown, Emily L Wilson, Angela P Presson, Victor D Dinglas, Tom Greene, Ramona O Hopkins, Dale M Needham, with the National Institutes of Health NHLBI ARDS Network

Results: severity of physical & mental impairment closely tied

- **4 post-ARDS outcome subtypes:**
 - Mildly impaired physical & mental health (22%)
 - Moderately impaired physical & mental health (39%)
 - Severely impaired physical & moderately impaired MH (15%)
 - Severely impaired physical & mental health (24%)
- Cognitive function not associated with subtypes
- ICU variables/severity of illness not associated with subtypes
- Baseline differed among sub-types; **each subtype had decrement**

Fatigue Symptoms During the First Year after ARDS

Neufeld K, Leoutsakos JM, Yan H, Lin S, Zabinski J, Dinglas V, Hosey MM, Parker A, Hopkins R. Needham D

Chest 2020

- **Prospective** study at 38 US hospitals (2008-2014)
- Patients (**n=732**): ~49yo, MV ~11d, Hosp LOS~22d
- 6 & 12 mo. outcomes measures: FACIT-F (fatigue)

Results (**≥94% response rate**):

- At 6 & 12 mo: **70% & 66%** fatigue
- 12 mo: 28% worsen; 31% no change, 41% improve

NO association: with ICU or ARDS severity

Fatigue Symptoms During the First Year after ARDS

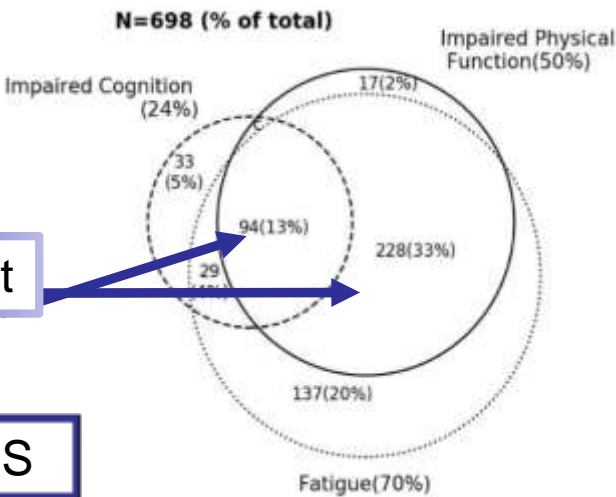
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Chest 2020

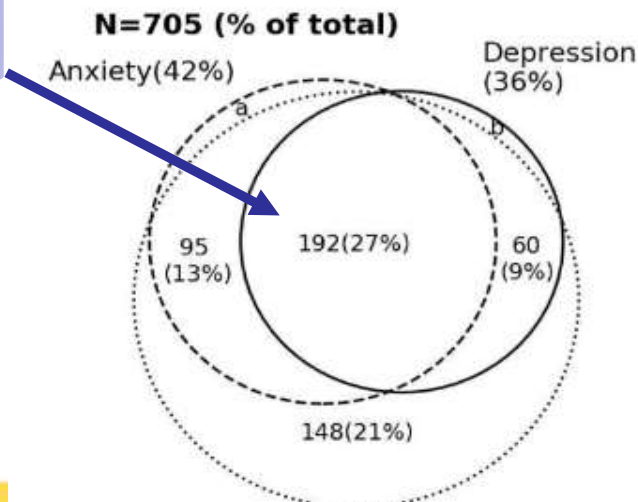
- Prospective study at 38 US hospitals (2008-2014)
- Patients (n=732): ~49yo, MV ~11d, Hosp LOS~22d

46% Fatigue & Physical Impairment

6 months post ARDS

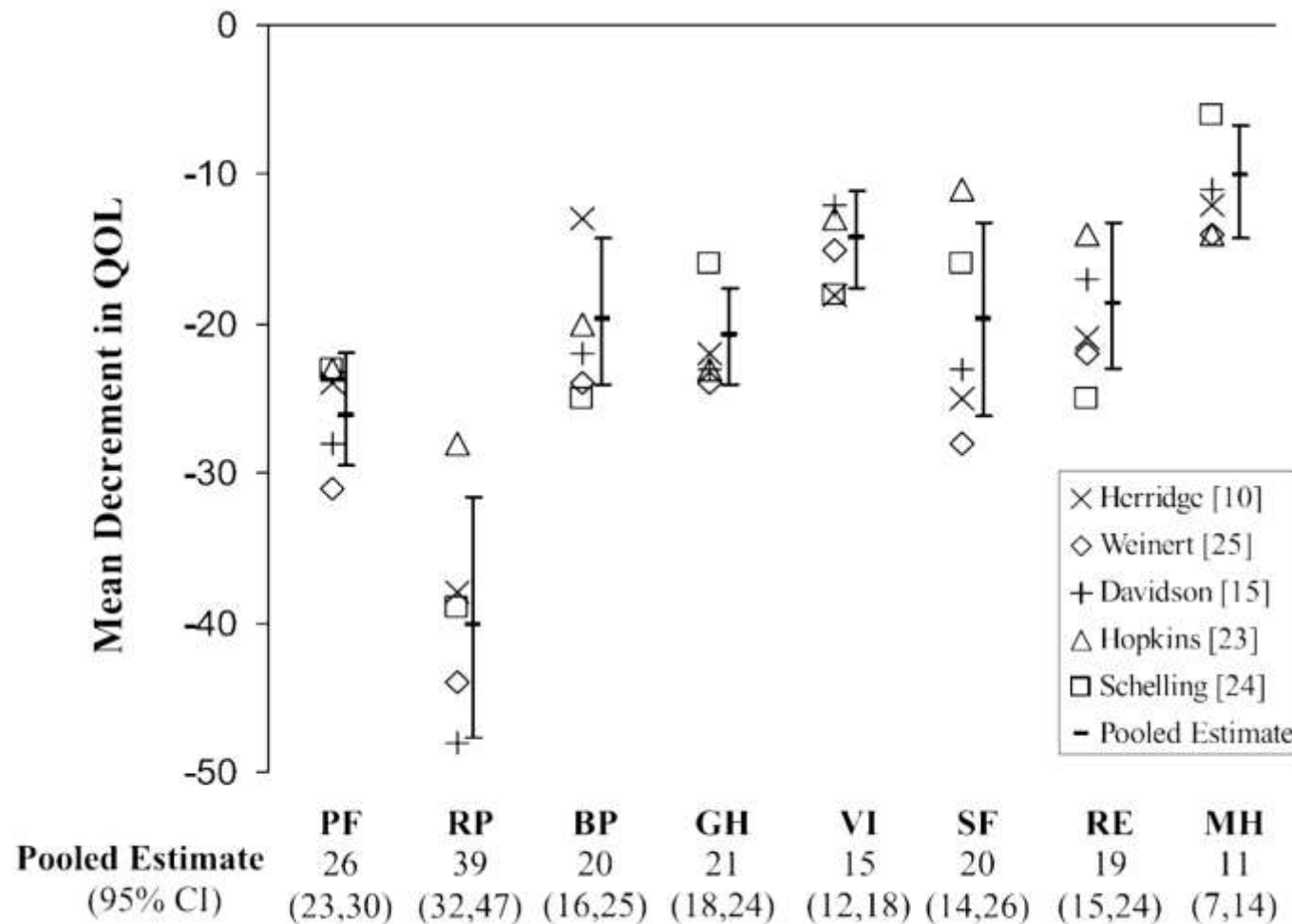


27% Fatigue, Anxiety & Depression



Quality of Life (decreases from norms)

Meta-analysis: SF-36 1-4 year after ARDS



Return to Work after Critical Illness:

Systematic Review and Meta-analysis



Thorax 2020

BB Kamdar, R Suri, MR Suchyta, KF Digrande, KD Sherwood,
E Colantuoni, VD Dinglas, DM Needham, RO Hopkins

52 studies in 10,015 previously-employed ICU survivors

- Proportion **NOT** returning to work after critical illness:
 - ~**2/3** at 1-3 months,
 - ~**1/3** at 6 mo. to 5 years
- No difference in RTW for: ARDS status or Geographic (USA, EU, Au/NZ)
- Additional outcomes:
 - 20-36% lost job after returning to work
 - 17-66% had occupation change
 - 5-84% had worsening employment status (e.g., fewer work hours)
 - ~**70% accrued lost earnings** (~\$26k at 12 mo., ~\$180k at 60 mo.)

Next Steps for PICS

THE ACUTE RESPIRATORY FAILURE SURVIVOR **CORE OUTCOME MEASUREMENT SET**

WHAT IS IT?



A minimum set of outcomes and associated measurement instruments for use in all clinical research studies evaluating acute respiratory failure survivors.

HOW LONG DOES IT TAKE?



12 MINUTES
BY PHONE

HOW MUCH DOES IT COST?



\$ 1.50
PER ASSESSMENT

WHY USE IT?



Comparability of
your results with
other studies in
the field



Panel of 77
international stakeholders
(including patients, caregivers,
clinicians & researchers)
from >16 countries agree on
these essential measures



Make outcomes
research
STRONGER!

FOR MORE INFORMATION

✉ ImproveLTO@jhmi.edu 🌐 www.ImproveLTO.com 🐦 [@ImproveLTO](https://twitter.com/ImproveLTO)

Int'l Delphi Consensus:

25% patients, 25% clinicians, 50% researchers

www.improveLTO.com



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

Guidance on Composition of Panel

- PCORI (Patient-Centered Outcomes Research Institute)
- AHRQ (Agency for Healthcare Research & Quality)
- OMERACT (Outcome Measure in Rheumatology)

Other input

- External Advisory Committee
- InFACT (Int'l Forum for Acute Care Trialists)

Panel members (n=77)

- Clinical researchers (35*)
- Clinicians/Professional Assoc. (19[▲])
- Patients & Caregivers (19[▲])
- U.S. Fed Research Funding Org (4)

* From >16 countries (6 continents)

▲ From US, Canada, UK & Australia

Modified Delphi Consensus Process

GRADE Scale: *Not important* (1–3); *Important but NOT critical* (4–6); *Critical* (7–9); *Unable to score*
A priori consensus definition: ≥70% rated as Critical (≥7) **AND** ≤15% as Not important (≤3)

Stage 1: Core Outcome Set*

Stage 2: Core Outcome Measurement Set[§]

Preliminary Framework

- SCCM PICS (Post-Intensive Care Syndrome)
- NIH PROMIS (Patient-Reported Outcomes Measurement Info Sys.)
- WHO ICF (Int'l Classification of Functioning, Disability, and Health)

Survey

279 clinical researchers, ARDS survivors & family[†]

Qualitative interviews

48 ARF survivors[‡]

Scoping review[§]

of outcome measurement in ICU survivorship research

Information sheet

for each measure (e.g. cost, time, psychometrics)

Brief explanation of psychometric properties

Two Delphi Rounds

- 19 Outcomes + Panel suggested 8 outcomes
- Vote without consideration of availability, feasibility, ease of use, or psychometric properties
- Response rates: 97% and 99% in round 1 and round 2, respectively

Three Delphi Rounds

- 38 Measures + Panel suggested 37 measures
- Explicit consideration of the feasibility, ease of use, and psychometric properties of existing instruments
- Response rate: 91% - 97% across the 3 rounds

*Crit Care Med. 2017;45:1001-1010

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

‡Am J Crit Care. 2017;26:456-465.

§Thorax. 2017

§Crit Care Med. 2016;44:1267-77

For more information, visit www.improveLTO.com/coms/



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Source: @DrDaleNeedham (twitter)

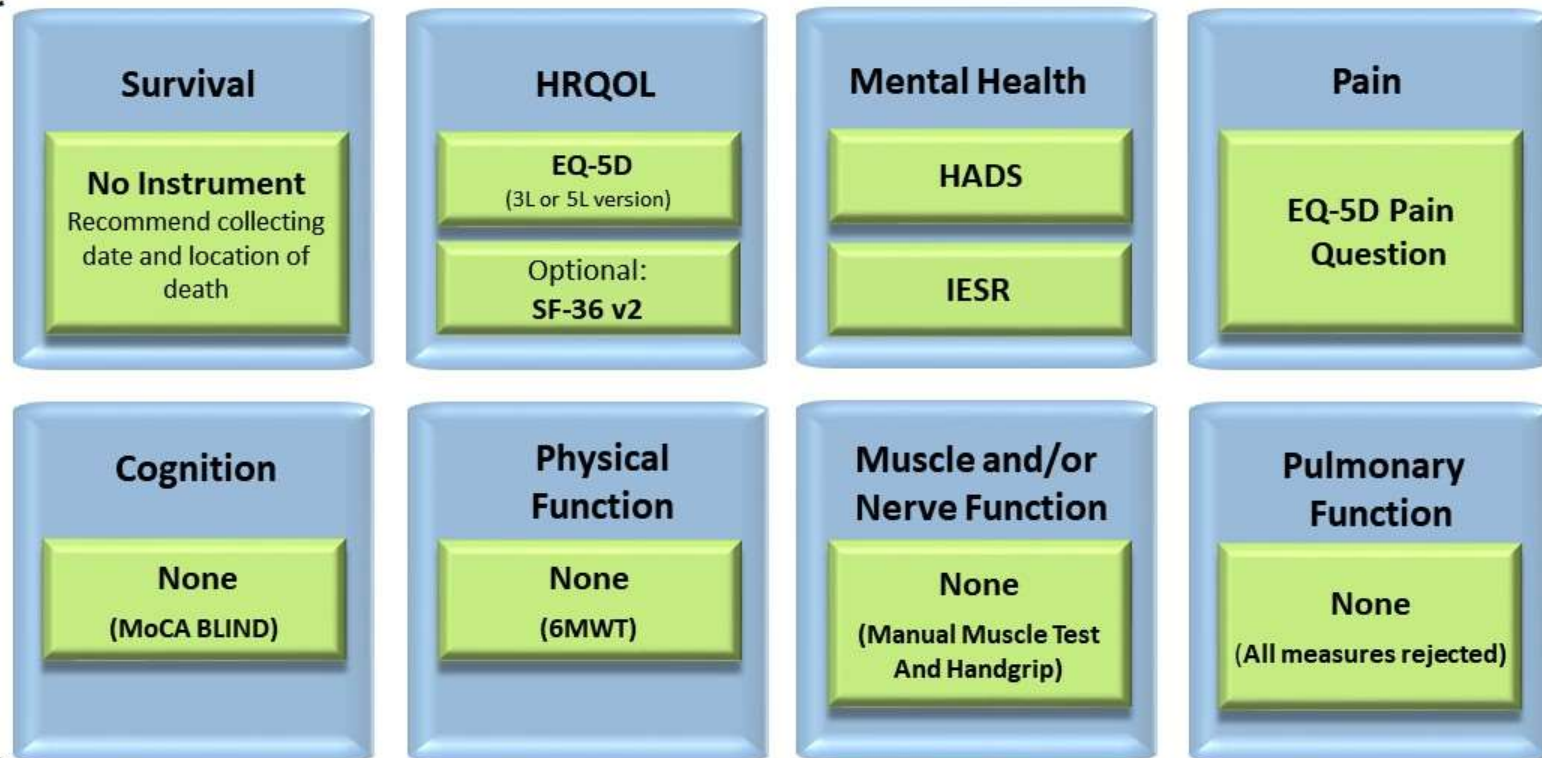
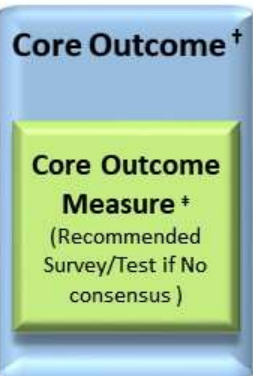
Next Steps for PICS

www.improveLTO.com

Core Outcome Set (COS) and Core Outcome Measurement Set (COMS) for Clinical Research in Acute Respiratory Failure Survivors

Improving Long-Term
Outcomes Research for
Acute Respiratory Failure

An NIH-Advanced Researcher-Resistant Research Project (ARRR) (U01HL111895)
Johns Hopkins University, University of Colorado Denver, and University of Michigan



[†] *Crit Care Med.* 2017; 45:1001-1010 ^{*} *Am J Resp Crit Care Med.* 2017;196:1122-1130.



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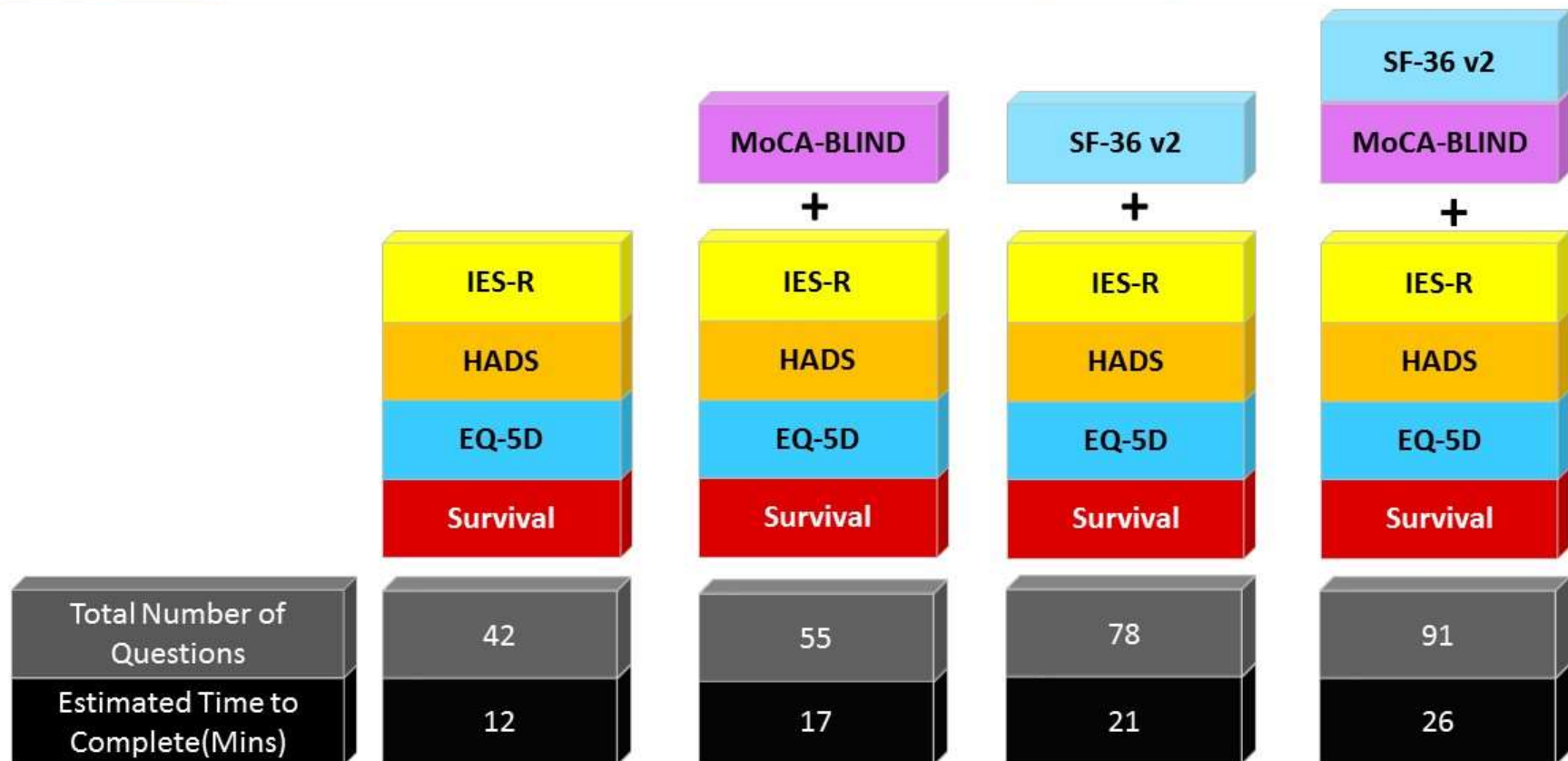
Source: @DrDaleNeedham (twitter)

Next Steps for PICS

www.improveLTO.com



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



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



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Source: @DrDaleNeedham (twitter)

Risk factors for Post-intensive care syndrome: A systematic review and meta analysis.

Aus Crit Care 2020

Minju Lee PhD, Jiyeon Kang PhD, Jin Jeong PhD.

- **Design:** English articles from 2008-2018; 2/3 from last 5 years
- **Results:** 119,049 articles screened; **89 eligible studies**
 - **Geography:** ~40% from each of USA & Europe
 - **Quality:** 80% “good” (Newcastle-Ottawa scale)
 - **Sample size:** 61% N=100-300; 30% single ICU
 - **Follow-up:** most 1 time point only; ~70% at ≤6 mo. time
- **Domain:** 90% assessed only 1; ~40% mental, 40% physical, 20% cognitive
- **Risk factors:** 60 different factors; 50/50 for patient/ICU risk factors
 - **Most not modifiable...**
 - **Physical:** older age, severity of illness
 - **Mental health:** female, prior MH problem, negative ICU experience
 - **Cognitive:** delirium

Nonpharmacologic Interventions to Prevent or Mitigate Adverse Long-Term Outcomes Among ICU Survivors: Sys Review

Wyske W. Geense, MSc; Mark van den Boogard, PhD; Johannes G. van der Hoeven, MD, PhD; Hester Vermeulen, PhD; Gerjon Hannink, PhD; Marieke Zegers, PhD

CCM 2019

- **Aim:** Assess effectiveness of non-pharma Tx for outcomes post-discharge
- **Results:** 5,165 pt in 36 studies (95% RCT; 56% single-center)
- **Risk of bias:** Incomplete data in 50% of studies
- **Intervention in 36 (%) studies**

ICU (44%), Post-ICU (22%), Post-hosp (31%)	
Exercise/physical rehab	56%
Follow-up services	14%
Psychosocial	8%
Diaries	8%
Information/education	6%

Outcomes: 73 instruments

49 used once; 7 PTSD, 6 QOL <3mo. (81%), 3-6 (56%), >6 (22%)	
Quality of Life	47%
Mental Health	36%
Physical Health	28%
Cognitive Health	11%

- **Conclusion:** Non-pharma for LTO NEW (only 34 RCT for any outcome)
reduce loss to follow-up & standardize instrument (www.improveLTO.com)

Source: @DrDaleNeedham (twitter)

Not just the ICU...

Post-Hospital Syndrome — An Acquired, Transient Condition of Generalized Risk

Harlan M. Krumholz, M.D.

N ENGL J MED 368;2 NEJM.ORG JANUARY 10, 2013

The New England Journal of Medicine