



Core Outcomes for Clinical Research in Acute Respiratory Failure Survivors

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NHLBI Grant: R24HL111895

Create and nationally disseminate resources to assist Acute Respiratory Distress Syndrome (ARDS)/Acute Respiratory Failure (ARF) researchers in designing trials that appropriately evaluate long-term patient outcomes

> Improving Long-Term Outcomes Research for Acute Respiratory Failure

An NHLBI-funded Resource-Related Research Project (R24HL111895)

Johns Honkins University's Outcomes After Critical Illness and Surgery (OACIS) Group

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R24 Grant Aims

Aim 1: Web-based electronic database of validated and recommended survey instruments and clinical testing methods for long-term outcomes

Aim 2: Practical resources for maximizing retention in long-term, longitudinal research

Aim 3: Statistical methods & programs for evaluating functional outcomes in the presence of high patient mortality ("competing risk of mortality")

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Outcome measurement in ICU survivorship research from 1970-2013: a scoping review of 425 publications Turnbull et al. *Crit Care Med.* 2016:44:1267-77



Peer-reviewed published studies 1970 - 2013

 ≥ 20 adult ICU survivors assessed after hospital discharge

Excluded

- Qualitative studies
- Studies only assessing survival
- Psychometric evaluations of measurement instruments or tests
- >50% of patients had neurologic injury
- >50% of patients had cardiac surgery

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Outcome measurement in ICU survivorship research from 1970-2013: a scoping review of 425 publications Turnbull et al. Crit Care Med. 2016;44:1267-77



425 peer-reviewed papers

· Outcomes assessed using 250 different measurement instruments

Why is this a problem?

- Difficult to compare results
- Barrier to meta-analyses
- Selective outcome reporting bias

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Our goal

Develop a core set of outcomes and related measures for survivors of acute respiratory failure (including ARDS) after hospital discharge using a rigorous methodology and an international panel of relevant stakeholders.

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Definitions

• Core outcome - a concept, health-related condition, or aspect of health that must always be measured within a specific field of research

(What outcomes should we all measure?)

Core measure – a measurement instrument selected to assess a core outcome (How should we measure them?)

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CORE MEASURE SET (CMS)

Core measure set: A minimum collection of agreed-upon measures (for core outcomes) reported in all studies within a specific field.

A CMS does NOT prevent investigators from collecting data on additional outcomes.

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Work informing CMS development

- Scoping review
- Systematic reviews
- · Psychometric evaluations of existing instruments
- Qualitative interviews with ARDS survivors

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Modified Delphi Consensus Process

Uses expert opinion to address questions for which empirical data are unavailable or inadequate



Delphi – Expert Panel

Stakeholder groups

- 1. Clinical researchers (n=35)
 - All International Forum for Acute Care Trialists (InFACT) members
 - ii. Random sample of 6 corresponding authors from scoping review
 - iii. 9 authors of internationally recognized ARF research
 - iv. >16 countries represented
- 2. Clinicians/professional associations (n=19)
 - i. ICU physicians, ICU nurses, rehabilitation clinicians
 - ii. Australia, Canada, UK, & US
- 3. Patients/caregivers (n=17)
 - i. Australia, Canada, UK, & US
- 4. Funding bodies (n=4)

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Delphi Methodology

- · Each outcome rated using GRADE scale
 - (1-3) = Not Important
 - (4-6) = Important but not Critical
 - (7-9) = Critical

Unable to score

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Delphi Methodology

a priori consensus definition

≥70% rated outcome as Critical (≥7)

And
≤15% rated outcome as Not important (≤3)

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Delphi Methodology

- 1. All voting conducted online
- 2. Anonymity maintained
- 3. No consideration of the availability, ease of use, feasibility, or properties of available instruments

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Phase I: Round 1

Before voting, review:

- Survey of corresponding authors of publications regarding potential core outcomes
- Phone-based survey of ARF survivors and caregivers about potential core outcomes
- Summary of qualitative study of ARF survivors regarding key outcomes

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Phase I: Round 1

Then:

- Rate each of 19 preliminary outcomes from
 - Patient Reported Outcome Measurement Information System (PROMIS)
 - WHO's International Classification of Functioning, Disability, & Health (ICF)
 - SCCM's Post-Intensive Care Syndrome (PICS) framework
 - Clinician, researcher and patient input
- Option of proposing additional outcomes

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Phase I: Round 1 - Results

- 96% participation rate
- 7 outcomes met consensus criteria
- 8 new outcomes suggested
- No outcomes dropped from consideration

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Round 1 Survey Results by Stakeholder Group (96% response rate)

| | Score | Proportion of stakeholders rating the outcome ≥7 on a 9-point Likert scale | | | | | |
|--|---------------------|--|-----------------------------------|--|--------------------------------------|--|--------------------------------------|
| - | | | | | US Federal | | |
| Outcomes | Mean (SD) (n=74) | All Panel Members (n=74) | Clinical Researchers (n=33) | Professional Associations (n=19) | Patients and Caregivers (n=18) | Research Funding Organizations (n=4) | |
| | | | | | | | Outcomes meeting consensus criteria* |
| Cognitive function and symptoms | 8.1 (1.1) | 68 (92%) | 32 (97%) | 18 (95%) | 14 (78%) | 4 (100%) | |
| Physical function and symptoms | 8.1 (1.0) | 66 (89%) | 30 (91%) | 17 (89%) | 15 (83%) | 4 (100%) | |
| Mental health conditions and symptoms | 7.9 (1.0) | 64 (86%) | 30 (91%) | 16 (84%) | 14 (78%) | 4 (100%) | |
| Survival | 7.9 (1.6) | 56 (76%) | 31 (94%) | 14 (74%) | 9 (50%) | 2 (50%) | |
| Pain | 7.2 (1.5) | 54 (73%) | 23 (70%) | 15 (79%) | 13 (72%) | 3 (75%) | |
| Muscle and/or nerve function | 7.3 (1.5) | 52 (70%) | 23 (70%) | 12 (63%) | 13 (72%) | 4 (100%) | |
| Pulmonary function and symptoms | 7 (1.6) | 52 (70%) | 20 (61%) | 14 (74%) | 15 (83%) | 3 (75%) | |
| Outcomes not meeting consensus criteria ^a | | | | | | | |
| Satisfaction with life, or personal enjoyment | 7.1 (1.4) | 51 (69%) | 21 (64%) | 14 (74%) | 14 (78%) | 2 (50%) | |
| Return to work or prior activities | 6.9 (1.6) | 45 (61%) | 24 (73%) | 11 (58%) | 8 (44%) | 2 (50%) | |
| Fatigue | 6.8 (1.7) | 44 (59%) | 20 (61%) | 11 (58%) | 11 (61%) | 2 (50%) | |
| Impact on family and/or caregivers | 6.7 (1.7) | 40 (54%) | 17 (52%) | 11 (58%) | 11 (61%) | 1 (25%) | |
| Swallowing function and symptoms | 6.4 (1.8) | 37 (50%) | 15 (45%) | 9 (47%) | 11 (61%) | 2 (50%) | |
| Financial impact on patient | 6.2 (1.9) | 35 (47%) | 13 (39%) | 7 (37%) | 14 (78%) | 1 (25%) | |
| Healthcare resource utilization | 6.3 (1.7) | 35 (47%) | 16 (48%) | 5 (26%) | 12 (67%) | 2 (50%) | |
| Sleep function and symptoms | 6.3 (1.6) | 35 (47%) | 16 (48%) | 7 (37%) | 10 (56%) | 2 (50%) | |
| Social roles, activities or relationships | 6.3 (1.8) | 34 (46%) | 17 (52%) | 7 (37%) | 9 (50%) | 1 (25%) | |
| Type of residence | 6.2 (1.8) | 32 (43%) | 13 (39%) | 10 (53%) | 8 (44%) | 1 (25%) | |
| Gastrointestinal function and symptoms | 5.5 (1.8) | 21 (28%) | 7 (21%) | 5 (26%) | 7 (39%) | 2 (50%) | |
| Sexual function and symptoms | 4.8 (1.8) | 11 (15%) | 3 (9%) | 2 (11%) | 5 (28%) | 1 (25%) | |

Sexual function and symptoms 4.8 (1.8) 11 (15%) 3 (9%) 2 (11%) 5 (28%) 1 (25*

*The consensus criteria for inclusion as a core outcome was defined as 270% of all panel members rating an outcome 27 and no more than 15% rating the outcome 53 on a 9-point scale.

Outcomes are ordered by the proportion of panel members rating the outcome 27.

*A total of 7 of 74 (9%) unique panel members ever selected "Unable to Score." The number of panel members selecting "Unable to Score" by outcome: Physical function and symptoms (1), Memtal health conditions and symptoms (1), Survival (3), Muscke and/or rever function (1), Pulmorary function and symptoms (1), Return to work or prior activities (3), Impact on family and/or caregivers (3), Swallowing function and symptoms (1), Setting the outcome 27 and 5 (3), Impact on family and/or caregivers (3), Swallowing function and symptoms (1), Swallowing function and







Phase I: Round 2

Before voting, review:

Your Round 1 response compared to:

- aggregate responses for the entire panel
- aggregate responses of each stakeholder group

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Phase I: Round 2

Then:

Rate each of 19 preliminary outcomes and the 8 newly suggested outcomes

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Phase I: Round 2 - Results

- 97% participation rate
- 7 outcomes met consensus inclusion criteria
- No newly suggested outcomes met inclusion criteria

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| | Score | Proportion of stakeholders scoring the outcome ≥7 on a 9-point Likert scale | | | | | |
|--|-----------|---|-------------|--------------|--------------|------------------|--|
| - | | Clinicians / US Fed | | | | | |
| | | All Panel | Clinical | Professional | Patients and | Research Funding | |
| | Mean (SD) | Members | Researchers | Associations | Caregivers | Organizations | |
| Outcome | (n=75) | (n=75) | (n=35) | (n=19) | (n=17) | (n=4) | |
| Outcomes meeting consensus criteria ^a | | (11-73) | (11-33) | (11-13) | | (11-4) | |
| Physical function and symptoms | 8.4 (0.8) | 73 (97%) | 34 (97%) | 18 (95%) | 17 (100%) | 4 (100%) | |
| Cognitive function and symptoms | 8.4 (0.9) | 71 (95%) | 34 (97%) | 18 (95%) | 15 (88%) | 4 (100%) | |
| Mental health conditions and symptoms | 8.0 (0.8) | 70 (93%) | 33 (94%) | 18 (95%) | 15 (88%) | 4 (100%) | |
| Survival | 8.2 (1.3) | 64 (85%) | 35 (100%) | 16 (84%) | 10 (59%) | 3 (75%) | |
| Pulmonary function and symptoms | 7.3 (1.4) | 64 (85%) | 29 (83%) | 14 (74%) | 17 (100%) | 4 (100%) | |
| Pain | 7.5 (1.4) | 63 (84%) | 29 (83%) | 17 (89%) | 14 (82%) | 3 (75%) | |
| Muscle and/or nerve function | 7.3 (1.1) | 62 (83%) | 27 (77%) | 16 (84%) | 15 (88%) | 4 (100%) | |
| Outcomes not meeting consensus criteria ^a | 7.3 (1.4) | 02 (03/0) | | 10 (04/0) | 13 (00/0) | 4 (100%) | |
| Satisfaction with life, or personal enjoyment | 7.2 (1.2) | 52 (69%) | 22 (63%) | 14 (74%) | 14 (82%) | 2 (50%) | |
| Impact on family and/or caregivers | 7.1 (1.4) | 50 (67%) | 23 (66%) | 12 (63%) | 13 (76%) | 2 (50%) | |
| Fatigue | 6.9 (1.4) | 49 (65%) | 23 (66%) | 12 (63%) | 12 (71%) | 2 (50%) | |
| Return to work or prior activities | 7.0 (1.3) | 48 (64%) | 23 (66%) | 13 (68%) | 10 (59%) | 2 (50%) | |
| Swallowing function and symptoms | 6.7 (1.6) | 47 (63%) | 20 (57%) | 11 (58%) | 13 (76%) | 3 (75%) | |
| Financial impact on patient | 6.7 (1.5) | 43 (57%) | 19 (54%) | 8 (42%) | 15 (88%) | 1 (25%) | |
| Healthcare resource utilization | 6.6(1.2) | 41 (55%) | 20 (57%) | 7 (37%) | 12 (71%) | 2 (50%) | |
| Sleep function and symptoms | 6.4 (1.4) | 38 (51%) | 17 (49%) | 7 (37%) | 12 (71%) | 2 (50%) | |
| Social roles, activities or relationships | 6.6 (1.3) | 37 (49%) | 19 (54%) | 6 (32%) | 11 (65%) | 1 (25%) | |
| Type of residence | 6.3 (1.6) | 30 (40%) | 12 (34%) | 9 (47%) | 8 (47%) | 1 (25%) | |
| Gastrointestinal function and symptoms | 5.5 (1.5) | 16 (21%) | 4 (11%) | 5 (26%) | 6 (35%) | 1 (25%) | |
| Sexual function and symptoms | 4.9 (1.2) | 7 (9%) | 3 (9%) | 0 (0%) | 4 (24%) | 0 (0%) | |
| Outcomes suggested by stakeholders during Round : | | | 3 (370) | 0 (070) | - (±4/0) | S (070) | |
| Fatigability / endurance | 6.9 (1.4) | 47 (63%) | 19 (54%) | 12 (63%) | 14 (82%) | 2 (50%) | |
| Susceptibility to repeated infections | 6.7 (1.5) | 46 (61%) | 17 (49%) | 12 (63%) | 14 (82%) | 3 (75%) | |
| Renal Function | 6.5 (1.5) | 42 (56%) | 17 (49%) | 9 (47%) | 14 (82%) | 2 (50%) | |
| Self-efficacy/management | 6.4 (1.7) | 36 (48%) | 16 (46%) | 7 (37%) | 10 (59%) | 3 (75%) | |
| Management of Complex Medication Regimens | 6.2 (1.7) | 35 (47%) | 13 (37%) | 10 (53%) | 11 (65%) | 1 (25%) | |
| Resilience | 6.4 (1.7) | 34 (45%) | 14 (40%) | 6 (32%) | 12 (71%) | 2 (50%) | |
| Hearing | 5.8 (1.6) | 23 (31%) | 14 (40%) | 3 (16%) | 3 (18%) | 3 (75%) | |
| Loss of Taste | 5.6 (1.6) | 18 (24%) | 10 (29%) | 3 (16%) | 4 (24%) | 1 (25%) | |

Abbreviations: SD, Standard Deviation

The consensus criteria for inclusion as a core outcome was defined as ≥70% of all panel members rating a outcome ≥7 and no more than 15% rating the outcome ≤3 on a 9-point scale. Outcomes are ordered by the proportion of panel members series the outcome ≥7.

*A total of 4 of 7 is (5% longings panel members were selected "Unable to Score." Number of panel members selecting "Unable to Score" by outcome: Survival (1), Impact on family and/or caregiver (1), Hearing (1), and Management of complex subscriptions (1) and Management of complex subscriptions



| | Score | Proportion of stakeholders scoring the outcome ≥7 on a 9-point Liker | | | | |
|---|------------------------|--|------------------------|----------------------|-------------------------|-----------------------------|
| · | | | | Clinicians / | | US Federal |
| | | All Panel | Clinical | Professional | Patients and | Research Funding |
| | Mean (SD) | Members | Researchers | Associations | Caregivers | Organizations |
| Outcome | (n=75) | (n=75) | (n=35) | (n=19) | (n=17) | (n=4) |
| Outcome Nutcome meeting consensus criteria ^a | (11-73) | (11-73) | (11-33) | (11-13) | (!!-1/) | (11-4) |
| Physical function and symptoms | 8.4 (0.8) | 73 (97%) | 34 (97%) | 18 (95%) | 17 (100%) | 4 (100%) |
| | | | | | | |
| Cognitive function and symptoms | 8.4 (0.9) | 71 (95%) | 34 (97%) | 18 (95%) | 15 (88%) | 4 (100%) |
| Mental health conditions and symptoms | 8.0 (0.8) | 70 (93%) | 33 (94%) | 18 (95%) | 15 (88%) | 4 (100%) |
| Survival | 8.2 (1.3) | 64 (85%) | 35 (100%) | 16 (84%) | 10 (59%) | 3 (75%) |
| Pulmonary function and symptoms Pain | 7.3 (1.4) | 64 (85%) | 29 (83%) | 14 (74%) | 17 (100%) | 4 (100%) |
| | 7.5 (1.1) | 63 (84%) | 29 (83%) | 17 (89%) | 14 (82%) | 3 (75%) |
| Muscle and/or nerve function | 7.3 (1.2) | 62 (83%) | 27 (77%) | 16 (84%) | 15 (88%) | 4 (100%) |
| utcomes not meeting consensus criteria ^a | | | | | | |
| Satisfaction with life, or personal enjoyment | 7.2 (1.2) | 52 (69%) | 22 (63%) | 14 (74%) | 14 (82%) | 2 (50%) |
| Impact on family and/or caregivers | 7.1 (1.4) | 50 (67%) | 23 (66%) | 12 (63%) | 13 (76%) | 2 (50%) |
| Fatigue | 6.9 (1.4) | 49 (65%) | 23 (66%) | 12 (63%) | 12 (71%) | 2 (50%) |
| Return to work or prior activities | 7.0 (1.3) | 48 (64%) | 23 (66%) | 13 (68%) | 10 (59%) | 2 (50%) |
| Swallowing function and symptoms | 6.7 (1.6) | 47 (63%) | 20 (57%) | 11 (58%) | 13 (76%) | 3 (75%) |
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| Healthcare resource utilization | 6.6(1.2) | 41 (55%) | 20 (57%) | 7 (37%) | 12 (71%) | 2 (50%) |
| Sleep function and symptoms | 6.4 (1.4) | 38 (51%) | 17 (49%) | 7 (37%) | 12 (71%) | 2 (50%) |
| Social roles, activities or relationships | 6.6 (1.3) | 37 (49%) | 19 (54%) | 6 (32%) | 11 (65%) | 1 (25%) |
| Type of residence | 6.3 (1.6) | 30 (40%) | 12 (34%) | 9 (47%) | 8 (47%) | 1 (25%) |
| Gastrointestinal function and symptoms | 5.5 (1.5) | 16 (21%) | 4 (11%) | 5 (26%) | 6 (35%) | 1 (25%) |
| Sexual function and symptoms | 4.9 (1.2) | 7 (9%) | 3 (9%) | 0 (0%) | 4 (24%) | 0 (0%) |
| utcomes suggested by stakeholders during Round | 1 (none meeting co | | | | | |
| Fatigability / endurance | 6.9 (1.4) | 47 (63%) | 19 (54%) | 12 (63%) | 14 (82%) | 2 (50%) |
| Susceptibility to repeated infections | 6.7 (1.5) | 46 (61%) | 17 (49%) | 12 (63%) | 14 (82%) | 3 (75%) |
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| Resilience | 6.4 (1.7) | 34 (45%) | 14 (40%) | 6 (32%) | 12 (71%) | 2 (50%) |
| Hearing | 5.8 (1.6) | 23 (31%) | 14 (40%) | 3 (16%) | 3 (18%) | 3 (75%) |
| Loss of Taste | 5.6 (1.6) | 18 (24%) | 10 (29%) | 3 (16%) | 4 (24%) | 1 (25%) |
| bbreviations: SD, Standard Deviation The consensus criteria for inclusion as a core outcome wa: | s defined as ≥70% of a | all panel members rati | ng a outcome ≥7 and no | more than 15% rating | the outcome ≤3 on a 9 | -point scale. Outcomes are |
| rdered by the proportion of panel members rating the outc | ome ≥7. | | = | _ | | |
| A total of 4 of 75 (5%) unique panel members ever selecte learing (1), and Management of complex medication regime this work, created by Alison Turnbul, DVIII, | | | | | Survival (1), Impact on | family and/or caregiver (1) |

| | Score | Score Proportion of stakeholders scoring the outcome ≥7 on a 9-point Likert scale | | | | | |
|---|--------------------|---|-------------|--------------|--------------|------------------|--|
| | | Clinicians / US Fede | | | | | |
| | | All Panel | Clinical | Professional | Patients and | Research Funding | |
| | Mean (SD) | Members | Researchers | Associations | Caregivers | Organizations | |
| Outcome | (n=75) | (n=75) | (n=35) | (n=19) | (n=17) | (n=4) | |
| utcomes meeting consensus criteria | | (1-75) | (11-33) | | | | |
| Physical function and symptoms | 8.4 (0.8) | 73 (97%) | 34 (97%) | 18 (95%) | 17 (100%) | 4 (100%) | |
| Cognitive function and symptoms | 8.4 (0.9) | 71 (95%) | 34 (97%) | 18 (95%) | 15 (88%) | 4 (100%) | |
| Mental health conditions and symptoms | 8.0 (0.8) | 70 (93%) | 33 (94%) | 18 (95%) | 15 (88%) | 4 (100%) | |
| Survival | 8.2 (1.3) | 64 (85%) | 35 (100%) | 16 (84%) | 10 (59%) | 3 (75%) | |
| Pulmonary function and symptoms | 7.3 (1.4) | 64 (85%) | 29 (83%) | 14 (74%) | 17 (100%) | 4 (100%) | |
| Pain | 7.5 (1.1) | 63 (84%) | 29 (83%) | 17 (89%) | 14 (82%) | 3 (75%) | |
| Muscle and/or nerve function | 7.3 (1.2) | 62 (83%) | 27 (77%) | 16 (84%) | 15 (88%) | 4 (100%) | |
| utcomes not meeting consensus criteria ⁸ | | | | | | | |
| Satisfaction with life, or personal enjoyment | 7.2 (1.2) | 52 (69%) | 22 (63%) | 14 (74%) | 14 (82%) | 2 (50%) | |
| Impact on family and/or caregivers | 7.1 (1.4) | 50 (67%) | 23 (66%) | 12 (63%) | 13 (76%) | 2 (50%) | |
| Fatigue | 6.9 (1.4) | 49 (65%) | 23 (66%) | 12 (63%) | 12 (71%) | 2 (50%) | |
| Return to work or prior activities | 7.0 (1.3) | 48 (64%) | 23 (66%) | 13 (68%) | 10 (59%) | 2 (50%) | |
| Swallowing function and symptoms | 6.7 (1.6) | 47 (63%) | 20 (57%) | 11 (58%) | 13 (76%) | 3 (75%) | |
| Financial impact on patient | 6.7 (1.5) | 43 (57%) | 19 (54%) | 8 (42%) | 15 (88%) | 1 (25%) | |
| Healthcare resource utilization | 6.6(1.2) | 41 (55%) | 20 (57%) | 7 (37%) | 12 (71%) | 2 (50%) | |
| Sleep function and symptoms | 6.4 (1.4) | 38 (51%) | 17 (49%) | 7 (37%) | 12 (71%) | 2 (50%) | |
| Social roles, activities or relationships | 6.6 (1.3) | 37 (49%) | 19 (54%) | 6 (32%) | 11 (65%) | 1 (25%) | |
| Type of residence | 6.3 (1.6) | 30 (40%) | 12 (34%) | 9 (47%) | 8 (47%) | 1 (25%) | |
| Gastrointestinal function and symptoms | 5.5 (1.5) | 16 (21%) | 4 (11%) | 5 (26%) | 6 (35%) | 1 (25%) | |
| Sexual function and symptoms | 4.9 (1.2) | 7 (9%) | 3 (9%) | 0 (0%) | 4 (24%) | 0 (0%) | |
| utcomes suggested by stakeholders during Round | 1 (none meeting co | nsensus criteriaª) | | | | | |
| Fatigability / endurance | 6.9 (1.4) | 47 (63%) | 19 (54%) | 12 (63%) | 14 (82%) | 2 (50%) | |
| Susceptibility to repeated infections | 6.7 (1.5) | 46 (61%) | 17 (49%) | 12 (63%) | 14 (82%) | 3 (75%) | |
| Renal Function | 6.5 (1.5) | 42 (56%) | 17 (49%) | 9 (47%) | 14 (82%) | 2 (50%) | |
| Self-efficacy/management | 6.4 (1.7) | 36 (48%) | 16 (46%) | 7 (37%) | 10 (59%) | 3 (75%) | |
| Management of Complex Medication Regimens | 6.2 (1.7) | 35 (47%) | 13 (37%) | 10 (53%) | 11 (65%) | 1 (25%) | |
| Resilience | 6.4 (1.7) | 34 (45%) | 14 (40%) | 6 (32%) | 12 (71%) | 2 (50%) | |
| Hearing | 5.8 (1.6) | 23 (31%) | 14 (40%) | 3 (16%) | 3 (18%) | 3 (75%) | |
| Loss of Taste | 5.6 (1.6) | 18 (24%) | 10 (29%) | 3 (16%) | 4 (24%) | 1 (25%) | |
| bbreviations: SD, Standard Deviation | , , | . , , | . (==,-) | . (,) | , | ,=0,0) | |



Differing stakeholder perspectives

| Outcome | Clinical Researchers (n=35) | Clinicians / Professional Associations (n=19) | Patients and Caregivers (n=17) | US Federal Research Funding Organizations (n=4) |
|---------------------------------|--------------------------------|---|--------------------------------------|---|
| Financial impact on patient | 19 (54%) | 8 (42%) | 15 (88%) | 1 (25%) |
| Healthcare resource utilization | 20 (57%) | 7 (37%) | 12 (71%) | 2 (50%) |

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CORE OUTCOMES

- 1. Survival
- 2. Satisfaction with life, or personal enjoyment
- 3. Physical function and symptoms
- 4. Cognitive function and symptoms
- 5. Mental health conditions and symptoms
- 6. Pulmonary function and symptoms
- 7. Pain
- 8. Muscle and/or nerve function

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PHASE I results

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; *In Press*.

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If you're planning a study of ARF survivors: Contact us!

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