

Supplementary Document for

Critical Patient Outcomes to Evaluate after Acute Respiratory Failure: Perspectives of  
ARDS Survivors, Their Family, and Researchers

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**Supplementary Table 1. List of 19 outcome domains and additional descriptions provided to respondents**

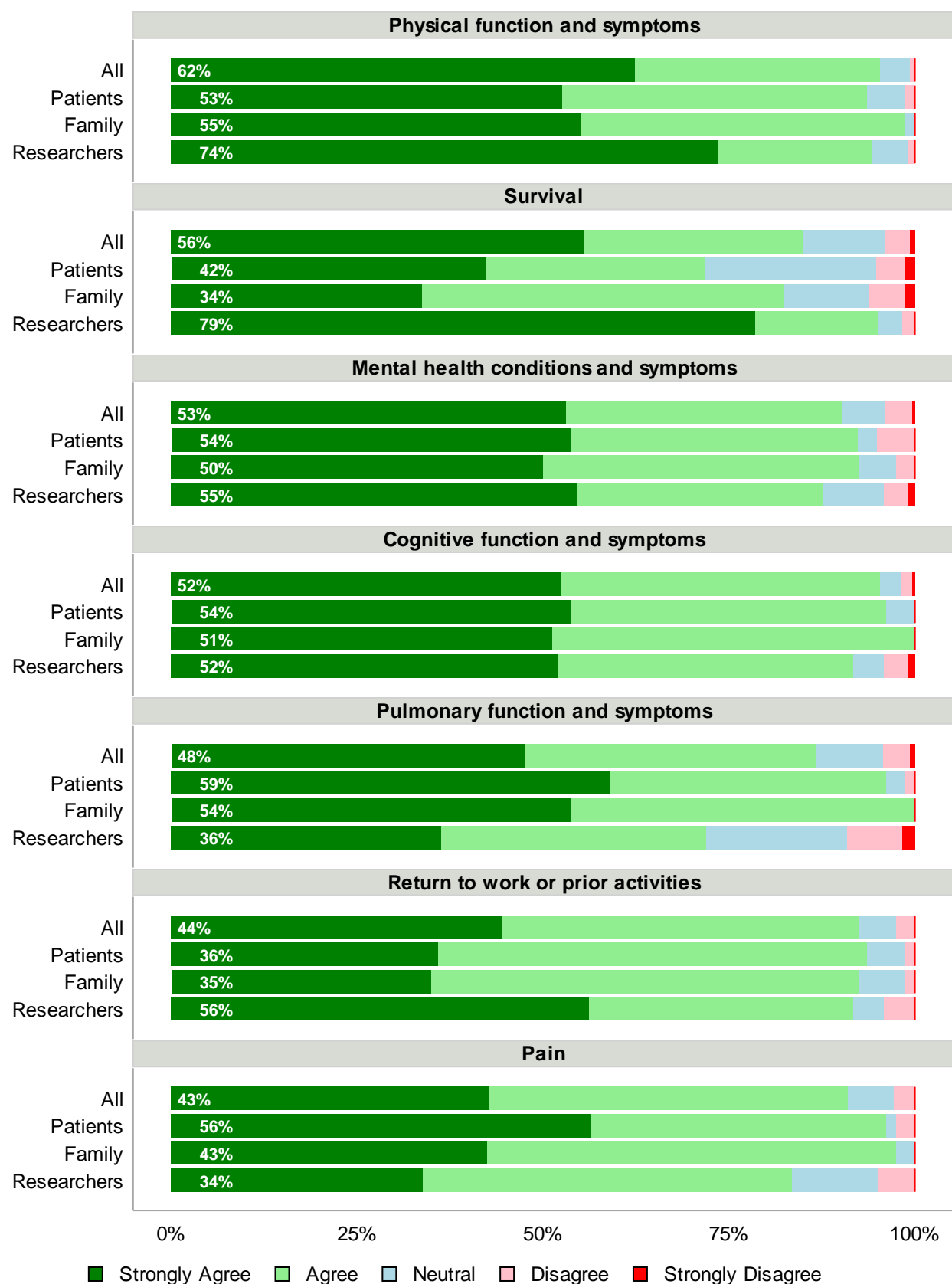
Survival (How long do people live after leaving the ICU?)
Pain
Fatigue (Are you feeling tired, having too little energy to get through the day, or needing more rest?)
Muscle and/or nerve function (Have you felt weak, sore, or numb?)
Physical function and symptoms (How easy it is to walk, dress, or eat?)
Pulmonary function and symptoms (Do you have trouble breathing, shortness of breath, or cough?)
Swallowing function and symptoms (Do you have any trouble swallowing foods or liquids?)
Gastrointestinal function and symptoms (Do you have stomachaches, nausea/vomiting, diarrhea, constipation, gas, or indigestion?)
Sleep function and symptoms (Do you have trouble falling asleep, staying asleep, or a need for a sleeping medication?)
Sexual function and symptoms (Do you have a decreased desire for sex, inability to have sex, or pain or discomfort during sex?)
Cognitive function and symptoms (Do you have problems with memory, communication, concentrating, or understanding instructions?)
Mental health conditions and symptoms (Do you have trouble with emotions and mood, anxiety, depression, posttraumatic stress disorder, or worrying?)
Type of residence (When you left the ICU, did you go to a rehabilitation center, nursing home, or to your own home?)
Return to work or prior activities (Are you doing the same things you did before the ICU? Did you return to your prior job full-time or part-time?)
Healthcare resource utilization (Are you seeing more doctors or physical therapists, taking new medications, or have you returned to the hospital? Do you need help making doctors' appointments?)
Financial impact on patient (Are you dealing with hospital bills or lost income from time off work? Do you have to pay someone to help with your care or transportation?)
Impact on family and/or caregivers (Do you feel you are a burden on family or friends? How does being sick affect other people in your life?)
Social roles, activities, or relationships (Are you still able to connect with others, maintain friendships, and romantic relationships? Able to complete activities with/for others?)
Satisfaction with life or personal enjoyment

**Supplementary Table 2. Demonstrating low kappa<sup>a</sup> despite relatively high exact agreement rate**

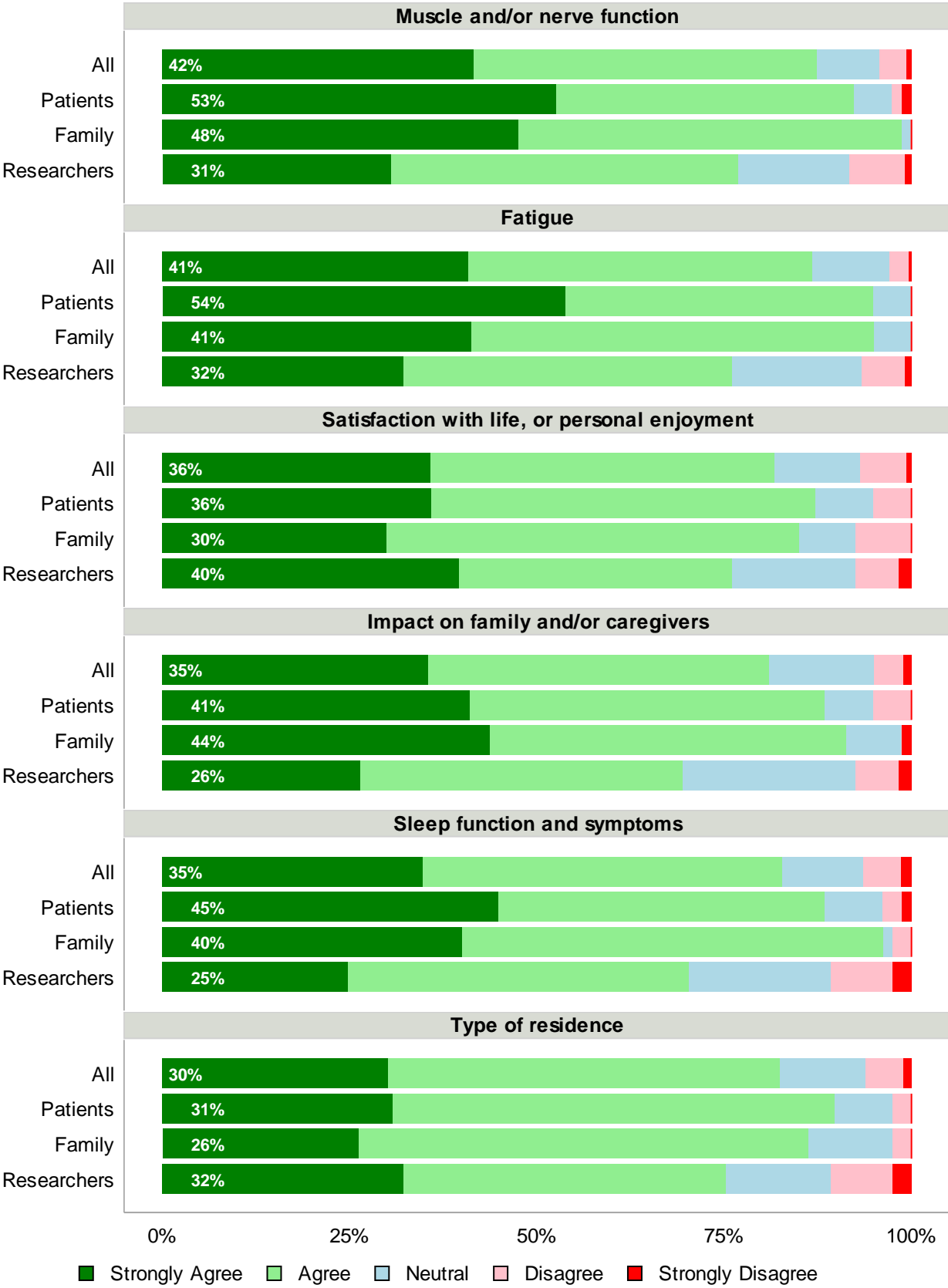
		Family				Total
		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Patient	Strongly Disagree	0	0	0	0	0
	Disagree	0	0	0	1	0
	Neutral	0	0	0	1	0
	Agree	0	0	1	12	7
	Strongly Agree	0	0	1	18	14
	Total	0	0	2	32	21

<sup>a</sup>For the Pain domain, kappa was 0.056 (95% confidence interval, -0.16 to 0.27) despite 47% exact agreement rate between patients and family. This is due to unbalanced marginal totals,(25) i.e. clustering towards one end of the scale. (Highlighted cells designate exact agreements.).

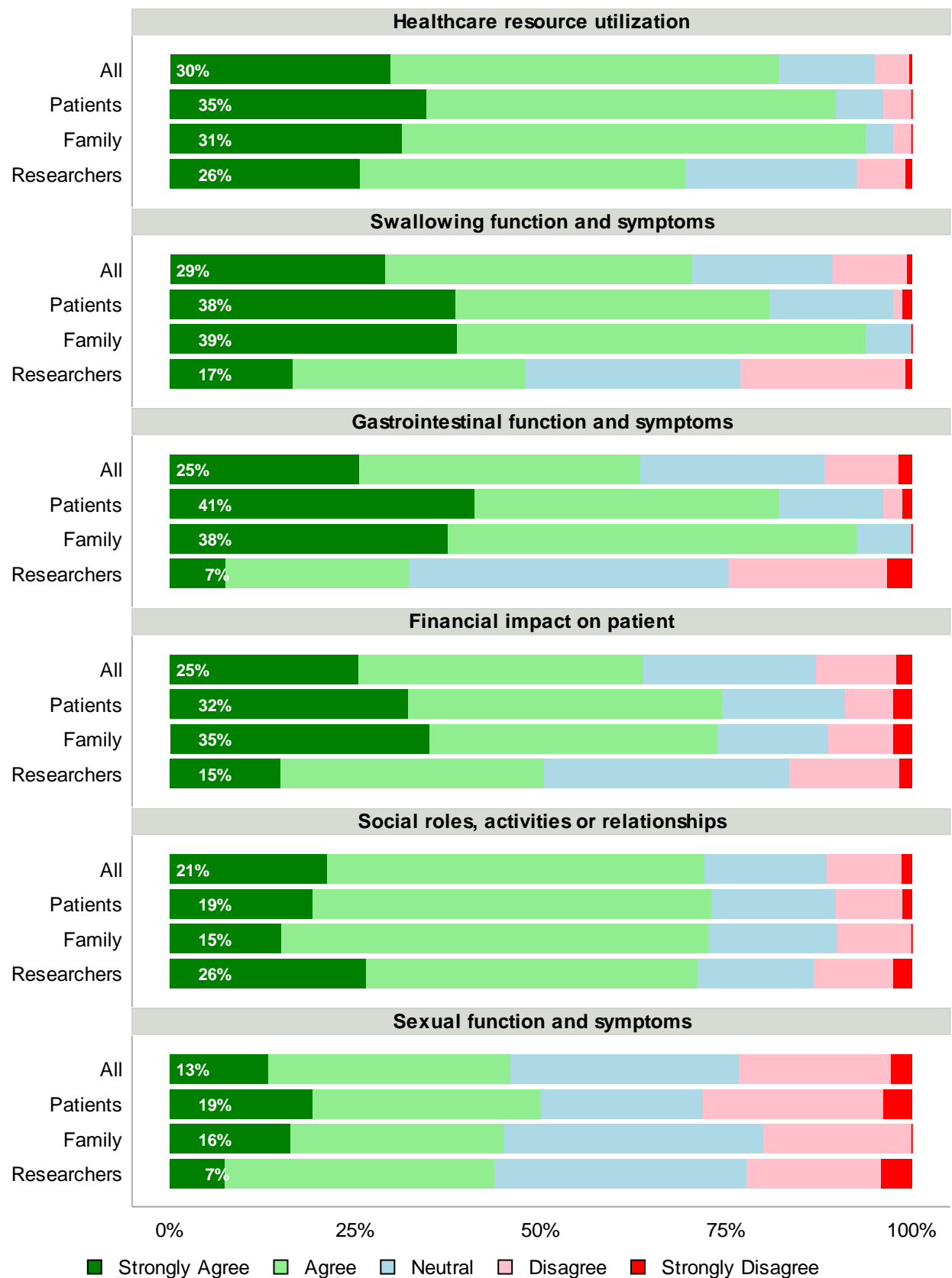
**Supplementary Figure.1 Support for requiring measurement of the domain in all studies of post-hospital survivorship in acute respiratory failure patients (page 1 of 3)**



Supplementary Figure.1 Support for requiring measurement of the domain in all studies of post-hospital survivorship in acute respiratory failure patients (page 2 of 3)



Supplementary Figure.1 Support for requiring measurement of the domain in all studies of post-hospital survivorship in acute respiratory failure patients (page 3 of 3)



**Supplementary Table3. Matched patient-family pairs (n=55)**

<b>Domain Questions</b>	<b>Number (%) with Exact Match in Score<sup>1</sup> within Pair</b>	<b>Number (%) with ≤1 Point Difference in Score<sup>1</sup> within Pair</b>
Cognitive function and symptoms	33 (60)	55 (100)
Physical function and symptoms	34 (62)	54 (98)
Pulmonary function and symptoms	34 (62)	54 (98)
Mental health conditions and symptoms	33 (60)	53 (96)
Pain	26 (47)	53 (96)
Fatigue	30 (55)	52 (95)
Return to work or prior activities	29 (53)	52 (95)
Muscle and/or nerve function	26 (47)	52 (95)
Healthcare resource utilization	27 (49)	51 (93)
Gastrointestinal function and symptoms	23 (42)	51 (93)
Type of residence	28 (51)	50 (91)
Impact on family and/or caregivers	30 (55)	49 (89)
Swallowing function and symptoms	24 (44)	49 (89)
Sleep function and symptoms	32 (58)	48 (87)
Satisfaction with life, or personal enjoyment	28 (51)	47 (85)
Financial impact on patient	23 (42)	46 (84)
Survival	22 (40)	44 (80)
Social roles, activities or relationships	26 (47)	43 (78)
Sexual function and symptoms	18 (33)	36 (65)

<sup>1</sup> Responses scored using a 5-point scale (“strongly disagree”, “disagree”, “neutral”, “agree”, and “strongly agree”) with higher score indicating greater agreement