Supplementary data.

Table 1. Detailed content of DANCAS surveys

Outcome domain	Outcome measure	Items, scoring	Danish translation	Notes
Survivors				
Generic health	EQ-5D-5L	Five item health dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Divided into five levels: 1='No problems' to 5= 'Extreme problems', scores ≥ 2 signifies a problem. Sixth item: Self-rating of health. Visual Analogue Scale, 0-100. Higher scores signify better health status.[1]	Received from the EuroQoL group	
Anxiety and depression	HADS	Seven-item symptoms of anxiety subscale (HADS-A) Seven-item subscale symptoms of depression (HADS-D). Four responses: 0='No symptoms' to 3= 'maximum number of symptoms'. Total subscale scores range: 0-21. <8 = no psychological distress, 8-10 = mild psychological distress, >10 definite psychological distress. It has recently been shown to be a valid measure of anxiety and depression in a Danish cardiac disease population.[2]	Received from DenHeart study group[3]	Valid measure of anxiety and depression in Danish cardiac disease population[3]

Supplemental material

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Mental recovery/dependency	TSQ	Yes to Q1a + Yes to Q1b signify new problems with dependency after cardiac arrest. No to Q2 indicates problems with mental recovery after cardiac arrest.[4][5]	Received from TTM2 study group[4]	-
Fatigue impact on functional activities	MFIS	21 items in three sub-scales (physical, cognitive and psychosocial). Total scores range: 0-84. Total subscale scores: physical= 0 -36; cognitive=0=40; psychosocial= 0-8. ≥30 signify a fatigued individual (Antmann, 2012, Schiehser, 2015)	Translation received from e Provide, Mapi Research Trust.	Validated in people with multiple sclerosis.[6] and mild to moderate brain injury.[7]
Function and disability	12-item WHO DAS 2.0	12-item assessing 6 domains of functioning: 1) Understanding and communication; 2) Self-care; 3) Mobility; 4) Interpersonal relationships; 5) Work and household roles; and 6) Community and civic roles. Scored from 0= 'no difficulty' to 4= 'extreme difficulty or cannot do'. Total scores range: 0-48. Higher score indicating greater difficulty with activity and participation.	Available from:https://www.etf.dk/ergoterapi-og-politik/hverdagsrehabilitering	Used extensively to research neurological conditions including traumatic brain injury and spinal cord injury,[8] and rehabilitation and disability in a wide range of disease populations.[9] Validated in patients with chronic diseases.[10]
Life satisfaction/rehabilitation need	REHPA scale	A linear analogue scale, participants indicate how close they are to living the life they desire after their OHCA. Scale ranges from 0= 'goal reached' to 9= 'infinitely far from'.	By DANCAS study authors	

		Score of ≤3 will be considered as signifying having rehabilitation needs.		
Unmet rehabilitation needs		6-items asking if rehabilitation needs were met in different domains, for example, emotional reactions. Scored on a 4-point Likert type scale from 'Yes to a high level' to 'No, not at all'.[12]	Adapted by DANCAS authors	Questions adapted from existing survey 'The Experience of Cancer Patients during Diagnosis and Treatment'.[12 13]
Unmet information needs	Adapted from Zinckernagel et al., 2017	7-items asking if information needs were met in different domains, for example, 'treatment of your heart condition' Scored on a 4-point Likert type scale from 'Yes to a high level' to 'No, not at all'.[14]	Adapted by DANCAS authors for OHCA survivors from a Danish survey of patients with heart disease.[14]	
Relatives				
Anxiety and depression	HADS	As above		
Mental well-being	WHO-5	Five items with 6 responses from 0='At no time' to 5='all of the time'. Scores are totaled and multiplied by 4 to give range 0-100. Score <50 signifies poor emotional well-being.[15]	Developed in Denmark.[16]	Valid in multiple patient populations.[17]

Cognitive problems in daily life	IQCODE-CA	26-items scored on a five-point scale, 1= 'much improved' to 5= 'much worse'. Scores are totaled, divided by the number of questions to give a total, range 1-5. Score ≥3.04 signifies cognitive decline after cardiac arrest.[18]	Received from TTM2 study group	Relatives or close friends compare current cognitive function with pre-cardiac arrest cognitive function. Has been shown to accurately identify cardiac arrest survivors with potential cognitive problems.[18]
Caregiver strain	MCSI	13-items, scored: 2= 'Yes, On a Regular Basis', 1= 'Yes, sometimes', 0= 'No'. Range: 0-26, higher scores signify a higher level of carer strain.[19]	Translated by DANCAS study authors[a]	Found to have high internal validity with a population of family caregivers.[19]
Witness to OHCA	Questions designed for this survey	1-item on whether they witnessed the OHCA	Created by DANCAS study authors	
Labour market	Questions designed for this survey	7-items on educational level completed, current labour market status, status in pre-OHCA period and details of any sick leave in post-OHCA period.	Created by DANCAS study authors	These questions are asked of the relatives as their survey answers cannot be connected to Danish labour market registry data unless they provide their Danish personal identification number.
Social isolation	Question from Danish national health survey	One item: Does it ever happen that you are alone even though you would prefer to be with other people?"	Available at: http://www.danskernessundhed.dk/Spoergeskema	

		Answers: "yes, often" and "yes, sometimes" signify loneliness. Other possible responses are "yes, but rarely" and "no.		
Support received post-OHCA	Questions designed for this survey	4-items on: whether relatives feel they have someone to talk to if they need support (yes, always/yes, mostly/yes, sometimes/no never or almost never); who have they received support from (multiple options); if they received the support they needed (Yes, No), and who would they have like to have received support from in the post-OHCA period (free text box).	Created by DANCAS study authors	

Abbreviations: HADS= Hospital Anxiety and Depression Scale; TSQ=Two Simple Questions; TTM2= Targeted Hypothermia versus Targeted Normothermia after OHCA trial 2; MFIS: Modified Fatigue Impact Scale, WHO DAS 2.0= World Health Organisation disability assessment schedule 2.0 Short; REHPA= Danish Knowledge Center for Rehabilitation and Palliative Care; OHCA=Out-of-hospital Cardiac Arrest; DANCAS=DANish Cardiac Arrest Survivorship; WHO-5= World Health Organisation-Five Well-Being index; IQCODE-CA: Informant Questionnaire on Cognitive Decline in the Elderly, Cardiac Arrest Version; MCSI= Modified Carer Strain Index.

[a]Translation, cultural adaption and psychometric testing performed by study authors, results are planned to be available in a future publication.

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