

Table S1. Ratings of relevance, content allocation and clarity by clinicians (n=10) and patients (n=9)

		Clinicians (n=10) QUANTITATIVE			Patients (n=9) QUALITATIVE			Synthesis & Adaptation
		Relevance	Designation to category	Clarity	Relevance	Coverage of content	Language Clarity	
1	Distress overall	good	NA	good	good	covered	good	
<b>TREATMENT</b>								
2	Treatment distress overall	good	correct	good	0.57	not covered	good	4 patients do not think of oxygen and / or medication → not adapted
3	Oxygen therapy	good	correct	good	good	covered	good	
4	Inhalation	good	correct	good	0.00	covered	good	
5	Antibiotics / steroids	0.67	correct	good	0.29	covered	good	
16	Missing collaboration with care team	good	correct	good	0.75	covered	good	
20	Lack of physical activity	good	0.00	0.70	good	not covered	good	4 patients understand daily items, e.g., 'household', but not 'training' → rephrased to 'lack of physical training'
<b>SYMPTOM</b>								
6	Coughing	good	correct	good	0.50	covered	good	
7	Phlegm	good	correct	0.70	good	covered	good	
8	Breathlessness	good	correct	good	0.67	covered	good	
9	Sleep disturbance	good	correct	good	good	covered	good	
10	Pain	good	correct	good	good	covered	good	
11	Lack of energy	good	0.67	good	0.60	covered	good	
12	Change in body weight	good	0.56	good	0.50	covered	good	
13	Incontinence urine	good	0.56	good	0.75	covered	not clear	3 patients did not understand 'incontinence' → rephrased to 'uncontrolled loss of urine'

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		Relevance	Designation to category	Clarity	Relevance	Coverage of content	Language Clarity	
14	Change in sexuality	good	0.50	good	0.25	covered	good	
<b>UNPREDICTABILITY</b>								
15	Lack of knowledge	0.7	correct	good	good	covered	good	
17	Threat due to progressing disease	good	0.63	good	0.33	covered	good	
18	Lack of current control	good	0.75	good	good	covered	good	
19	Lack of control in future	good	correct	good	0.75	covered	good	.
33	No impact on health condition	good	correct	0.78	0.50	covered	good	
34	Inability to fulfil recommendations	good	correct	good	good	not covered	good	2 patients do not understand what is meant → rephrased to '...recommendations regarding exercise, diet and smoking cessation'
<b>RESTRICTION IN DAILY LIFE</b>								
21	Restriction in daily freedom	good	0.75	good	good	covered	good	
22	Restriction in duties regarding work	good	0.75	good	0.75	covered	good	not relevant due to retirement → 'volunteering' added
23	Restriction in daily chores	good	0.78	good	good	covered	good	
24	Restriction in self-care	good	0.67	0.70	good	covered	good	
25	Restriction in care for others (humans or pets)	good	correct	good	0.67	covered	good	
26	Restriction in doing enjoyable things	good	0.44	good	0.50	covered	good	
27	Not meeting own expectations	good	correct	good	good	covered	good	
28	Being lonely	good	correct	good	good	covered	good	

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		Clinicians (n=10) QUANTITATIVE			Patients (n=9) QUALITATIVE			Synthesis & Adaptation
		Relevance	Designation to category	Clarity	Relevance	Coverage of content	Language Clarity	
29	Missing empathy	0.70	0.71	0.70	0.67	covered	good	
30	Not meeting expectations of others	good	correct	good	good	covered	good	
31	Burdening others	good	0.78	good	0.75	covered	good	
32	Unwanted attention	0.60	0.63	good	good	covered	good	
35	Self-inflicted condition	0.56	0.60	good	0.50	covered	good	
36	Others see condition as self-inflicted	0.70	0.71	0.70	0.63	covered	good	

Legend:

**Good / correct / covered:** The percentage of panellists who gave a favourable answer (3 = relevant / clear, 4 = very relevant / clear) or marked the corresponding category was  $\geq 0.8$ . As a total (100%), the number of panellists was counted who provided any answer (favourable / correct category; non-favourable / false category) for this item.

Table S2. Distribution of CRED-V1-Items

		Not applicable	0	1	2	3	4	5	Missing
CRED-V1_1_General illness-related emotional distress	Frequency	0	22	46	55	69	50	21	1
	Percentage	0	8.3	17.4	20.8	26.1	18.9	8	0.4
CRED-V1_2_Overall treatment distress	Frequency	0	69	49	55	63	14	8	6
	Percentage	0	26.1	18.6	20.8	23.9	5.3	3	2.3
CRED-V1_3_Oxygen therapy	Frequency	130	33	30	28	27	10	5	1
	Percentage	49.2	12.5	11.4	10.6	10.2	3.8	1.9	0.4
CRED-V1_4_Inhalation	Frequency	60	75	54	33	22	15	0	5
	Percentage	22.7	28.4	20.5	12.5	8.3	5.7	0	1.9
CRED-V1_5_Antibiotics / steroids	Frequency	130	56	26	25	11	9	5	2
	Percentage	49.2	21.2	9.8	9.5	4.2	3.4	1.9	0.8
CRED-V1_6_Coughing	Frequency	31	49	61	44	41	23	13	2
	Percentage	11.7	18.6	23.1	16.7	15.5	8.7	4.9	0.8
CRED-V1_7_Phlegm	Frequency	34	36	64	36	47	35	11	1
	Percentage	12.9	13.6	24.2	13.6	17.8	13.3	4.2	0.4
CRED-V1_8_Breathlessness	Frequency	13	14	25	52	66	65	27	2
	Percentage	4.9	5.3	9.5	19.7	25	24.6	10.2	0.8
CRED-V1_9_Sleep disturbance	Frequency	35	68	48	34	46	18	14	1
	Percentage	13.3	25.8	18.2	12.9	17.4	6.8	5.3	0.4
CRED-V1_10_Pain	Frequency	47	74	47	33	34	16	12	1
	Percentage	17.8	28	17.8	12.5	12.9	6.1	4.5	0.4

		Not applicable	0	1	2	3	4	5	Missing
CRED-V1_11_Lack of energy	Frequency	20	25	46	54	55	46	17	1
	Percentage	7.6	9.5	17.4	20.5	20.8	17.4	6.4	0.4
CRED-V1_12_Change in body weight	Frequency	44	76	40	32	34	21	16	1
	Percentage	16.7	28.8	15.2	12.1	12.9	8	6.1	0.4
CRED-V1_13_Uncontrolled loss of urine	Frequency	100	74	31	18	14	19	8	0
	Percentage	37.9	28	11.7	6.8	5.3	7.2	3	0
CRED-V1_14_Change in sexuality	Frequency	79	70	29	19	28	22	13	4
	Percentage	29.9	26.5	11	7.2	10.6	8.3	4.9	1.5
CRED-V1_15_Lack of knowledge	Frequency	76	93	46	24	15	4	4	2
	Percentage	28.8	35.2	17.4	9.1	5.7	1.5	1.5	0.8
CRED-V1_16_Missing collaboration with care team	Frequency	54	119	46	25	12	6	1	1
	Percentage	20.5	45.1	17.4	9.5	4.5	2.3	0.4	0.4
CRED-V1_17_Threat due to progressing disease	Frequency	27	67	37	45	48	27	13	0
	Percentage	10.2	25.4	14	17	18.2	10.2	4.9	0
CRED-V1_18_Lack of current control	Frequency	36	57	37	41	51	30	10	2
	Percentage	13.6	21.6	14	15.5	19.3	11.4	3.8	0.8
CRED-V1_19_Lack of control in future	Frequency	26	41	42	37	45	50	21	2
	Percentage	9.8	15.5	15.9	14	17	18.9	8	0.8
CRED-V1_20_Lack of physical training	Frequency	26	37	46	50	52	39	13	1
	Percentage	9.8	14	17.4	18.9	19.7	14.8	4.9	0.4
CRED-V1_21_Restriction in daily freedom	Frequency	25	32	43	40	48	52	23	1
	Percentage	9.5	12.1	16.3	15.2	18.2	19.7	8.7	0.4

		Not applicable	0	1	2	3	4	5	Missing
CRED-V1_22_Restriction in duties regarding work and volunteering	Frequency	118	47	21	23	15	21	15	4
	Percentage	44.7	17.8	8	8.7	5.7	8	5.7	1.5
CRED-V1_23_Restriction in daily chores	Frequency	53	63	35	31	34	32	15	1
	Percentage	20.1	23.9	13.3	11.7	12.9	12.1	5.7	0.4
CRED-V1_24_Restriction in self-care	Frequency	85	68	32	23	22	17	16	1
	Percentage	32.2	25.8	12.1	8.7	8.3	6.4	6.1	0.4
CRED-V1_25_Restriction in care for others	Frequency	81	64	28	29	22	22	17	1
	Percentage	30.7	24.2	10.6	11	8.3	8.3	6.4	0.4
CRED-V1_26_Restriction in doing enjoyable things	Frequency	36	37	32	48	30	49	29	3
	Percentage	13.6	14	12.1	18.2	11.4	18.6	11	1.1
CRED-V1_27_Not meeting own expectations	Frequency	33	48	38	51	36	32	25	1
	Percentage	12.5	18.2	14.4	19.3	13.6	12.1	9.5	0.4
CRED-V1_28_Being lonely	Frequency	78	92	26	23	19	16	8	2
	Percentage	29.5	34.8	9.8	8.7	7.2	6.1	3	0.8
CRED-V1_29_Missing empathy	Frequency	72	85	35	35	25	6	5	1
	Percentage	27.3	32.2	13.3	13.3	9.5	2.3	1.9	0.4
CRED-V1_30_Not meeting expectations of others	Frequency	52	72	33	41	30	23	9	4
	Percentage	19.7	27.3	12.5	15.5	11.4	8.7	3.4	1.5
CRED-V1_31_Burdening others	Frequency	49	55	35	37	38	36	13	1
	Percentage	18.6	20.8	13.3	14	14.4	13.6	4.9	0.4
CRED-V1_32_Unwanted attention	Frequency	55	89	43	29	24	16	7	1
	Percentage	20.8	33.7	16.3	11	9.1	6.1	2.7	0.4

		<b>Not applicable</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>Missing</b>
CRED-V1_33_No impact on health condition	Frequency	25	41	53	39	39	33	30	4
	Percentage	9.5	15.5	20.1	14.8	14.8	12.5	11.4	1.5
CRED-V1_34_Inability to fulfil recommendations	Frequency	66	68	39	30	31	21	8	1
	Percentage	25	25.8	14.8	11.4	11.7	8	3	0.4
CRED-V1_35_Self-inflicted condition	Frequency	29	55	29	37	49	38	24	3
	Percentage	11	20.8	11	14	18.6	14.4	9.1	1.1
CRED-V1_36_Others see condition as self-inflicted	Frequency	47	77	32	27	40	24	16	1
	Percentage	17.8	29.2	12.1	10.2	15.2	9.1	6.1	0.4