

Table S1. Questions included in the survey (VAS = Visual Analogue Scale, SD = standard deviation).

Items and responses	Total of respondents	Mean VAS score \pm SD	Frequency (%)
1. Have you felt pain or physical discomfort these last two weeks?	51		
Yes	25		49
No	26		51
2. If you feel pain, on which place(s) of your body is it? (several choices possible)	25		
Lower limb	21		84
Upper limb	6		24
Abdominals	4		16
Back	5		20
Head	7		28
Diffuse	2		8
3. Indicate on a scale ranging from 0 to 10 the intensity of the MOST INTENSE PAIN felt these last two weeks (0 = no pain, 10 = most intense pain)	25	6.16 \pm 2.44	
4. Indicate on a scale ranging from 0 to 10 the intensity of the LESS INTENSE PAIN felt these last two weeks (0 = no pain, 10 = most intense pain)	25	1.88 \pm 2.55	
5. Indicate on a scale ranging from 0 to 10 the intensity of the MEAN PAIN felt these last two weeks (0 = no pain, 10 = most intense pain)	25	4.20 \pm 1.98	
6. Does the pain have one or more of the following characteristics? (several choices possible)	25		
0 = no features	10		40
1 = burn	6		24
2 = painful cold sensation	4		16
3 = electrical shocks	10		40
7. Do you experience other symptom(s) in the painful area? (several choices possible)	25		
None	9		36
Tingling	5		20
Pinprick	6		24
Numbness	6		24
Itches	3		12
Feeling of vice	12		48
8. Do you feel a decrease in touch sensitivity in areas where pain is present?	25		
Decreased sensitivity during sting	20		80
Decreased sensitivity during simple touch	3		12
No decrease in sensitivity	2		8
9. Is pain caused or increased by friction?	25		
Yes	8		32
No	17		68
10. Indicate since when you feel these pains:	25		
1-15 days	0		0
15 days - 1month	0		0
1 -3 months	2		8
3 -6 months	6		24
6 months -1 year	5		20
> 1 year	12		48
11. Before the locked-in syndrome, did you already have these pains?	25		
Yes	2		8

No	21		84
I do not know	2		8
12. If you already had pain before the locked-in syndrome, indicate on a scale ranging from 0 to 10 the intensity of this pain (0 = no pain, 10 = most intense pain)	25	2.5 ± 2.08	
13. If you had this pain before, how did your pain progress following the locked-in syndrome?	4		
Aggravation of pain	0		0
Decrease of pain	2		50
Same pain	1		25
I do not know	0		0
14. The pain you are currently experiencing is:	25		
Punctual	21		84
Continue	4		16
If punctual, do you feel it:	21		
More than once a day	4		19
Once a day	2		9
Less than once a day	3		14.
I do not know	12		57
If punctual, do you feel it more:	21		
The morning	5		23
The afternoon	5		23
The evening	6		28
I do not know	5		23
15. When you are in pain, how do you express pain? (several choices possible)	25		
Winces	6		24
Cries	11		44
Look/blinking	4		16
Vocalizations	7		28
Communication code	7		28
No expression of pain	13		52
Other	2		8
16. When you feel pain, do you feel that certain elements increase the pain? (several choices possible)	25		
Mood/emotions	1		4
Temperature	4		16
Supine	3		12
Sitting	7		28
Care (nurses, physiotherapy, ...)	8		32
Touching	10		40
Tiredness	10		40
Physical exercises	8		32
Equipment (specific cushion, ...)	2		8
None	2		8
Other	3		12
17. When you feel pain, do you feel that certain elements decrease the pain? (several choices possible)	25		
Mood/emotions	0		0
Temperature	1		4
Supine	4		16
Sitting	6		24
Care (nurses, physiotherapy, ...)	2		8

Touching	10		40
Tiredness	5		20
Physical exercises	6		24
Equipment (specific cushion, ...)	3		12
None	3		12
Other	9		36
18. When you have pain, do you feel that pain affects your mental abilities? If yes, specify (several choices possible)	25		
Decreased concentration/attention	4		16
Increased mood swings	13		52
Decreased memory capacity	4		16
Depression	6		24
Tiredness	14		56
None	9		36
19. Does the pain disrupt your sleep?	25		
Yes	10		40
No	13		52
I do not know	2		8
20. If yes, indicate on a scale ranging from 0 to 10 how much the pain disturbs your sleep (0 = no influence, 1 = strong influence)	25	6.42 ± 3.23	
21. When you are in pain, do you feel that pain affects your emotions?	25		
Always	3		12
Sometimes	4		16
Rarely	14		56
Never	4		16
22. If yes, indicate on a scale ranging from 0 to 10 how pain affects your emotions (0 = no influence, 1 = strong influence)	25	4.68 ± 2.92	
23. Do you take any pharmacological treatment to ease your pain?	25		
Yes	15		60
No	10		40
24. If yes, how often do you take this treatment?	15		
Several times a day	5		33
Once a day	8		53
Occasionally, when the pain is too strong	2		13
25. If yes, indicate on a scale ranging from 0 to 10 how effective this (these) treatment(s) is (are) (0 = no influence, 1 = strong influence)	25	6 ± 2.93	
26. To relieve your pain, have you ever tried non-pharmacological treatments (example: meditation, hypnosis, etc.)?	25		
Yes	3		12
No	21		84
I do not know	1		4
27. If yes, indicate on a scale ranging from 0 to 10 how effective this (these) treatment(s) is (are) (0 = no influence, 1 = strong influence)	25	2 ± 1.73	
28. Do you want to test a new pharmacological or non-pharmacological treatment? (several choices possible)	25		
Yes, I would be ready to test a new pharmacological treatment	12		48
Yes, I would be ready to test a new non-pharmacological treatment	6		24
No, I wouldn't be ready to test a new pharmacological treatment	7		28
No, I wouldn't be ready to test a new non-pharmacological treatment	14		56