

Home ERT – Evaluation of satisfaction degree in patients with lysosomal storage diseases.

Name (initials)

Age

Sex

School degree

Diagnosis

- 1) Referring to your health concern, did you choose to undergo infusion therapy
 - a. At home
 - b. At the Referral Centre

- 2) Are you satisfied about your choice?
 - a. Yes
 - b. No
 - c. Not sure

- 3) How do you rate your satisfaction being infused at home or at the center (choose the closest degree)
 - a. Not at all satisfied
 - b. Quite unsatisfied
 - c. A little bit unsatisfied
 - d. Neither satisfied nor unsatisfied
 - e. A little bit satisfied
 - f. Quite satisfied
 - g. Totally satisfied

Please motivate your answer

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- 4) Since you decided, did you experience any benefit / changes?
 - a. Yes
 - b. No
 - c. Not sure

- 5) Please, specify the kind of changes (you can choose multiple answers)
 - a. Physical
 - b. Psychological
 - c. Familial relationship

- 6) How do you rate these changes?
 - a. Totally negative
 - b. Quite negative
 - c. A little bit negative
 - d. Neither negative - nor positive
 - e. A little bit positive
 - f. Quite positive

g. Totally positive
Please motivate your answer

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7) How do you evaluate the organization put in place by the Centre to allow Home Ert?

- a. Unsatisfactory
- b. Sufficient
- c. Discrete
- d. Good
- e. Excellent

Please motivate your answer

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8) Did you appreciate the psychological help offered by the Centre both in presence and on line?

- a. Yes
- b. No
- c. Indifferent

9) If you answered Yes to the previous question, how much did you appreciate this psychological help?

- a. Enterely unsatisfied
- b. Quite unsatisfied
- c. A little bit unsatisfied
- d. Indifferent
- e. A little bit satisfied
- f. Quite satisfied
- g. Enterely satisfied

10) Did you experience any change/benefit thanks to the psychological help?

- a. Yes
- b. No
- c. Not sure

11) Which kind of changes did you experience? (you can make multiple choises)

- a. Psychological
- b. Phisical
- c. Familial relationship

12) How do you rate the quality of these changes?

- a. Totally negative
- b. Quite negative
- c. A little bit negative
- d. Nor negative or positive

- e. A little bit positive
 - f. Quite positive
 - g. Totally positive
- Please motivate your answer

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13) How are you psychologically feeling at the current moment? How do you assess your health conditions?

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14) Considering your actual health and the still present pandemic, which would your feeling be in the event of a new lockdown?

- a. Resignation
- b. Anxiety
- c. Fear
- d. Distress
- e. Surprise
- f. Challenge
- g. Optimism

15) Have you made projects for your near future?

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16) How do you foresee your near future?

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17) What would you improve in the assistance and care of the Centre and its clinical staff?

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