

Appendix 2

Article Title: Living with facioscapulohumeral muscular dystrophy during the first two COVID-19 outbreaks, a repeated patient survey in the Netherlands

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Questions added to Survey 2 and 3.

- Did you complete a previous Corona questionnaire?
 - I completed a previous questionnaire
 - I am answering this questionnaire for the first time

- Who fills in this questionnaire?
 - Me
 - Spouse or family
 - Other,...

- Who is this other?

- What is your length in cm?

- What is your weight in kg?

- Is this domestic care or (also) personal care?
 - Domestic care
 - Also personal care (possibly combined with domestic care)

- Was it a voluntary isolation?
 - Voluntary isolation
 - Mandatory
 - Other

- Describe other isolation situation

- How much bodily exercise did you have during the Corona outbreak?
 - Substantially less bodily exercise than usual
 - Little less bodily exercise than usual
 - As much bodily exercise as usual
 - A bit more bodily exercise than usual
 - Substantially more bodily exercise than usual

- Who carried out the test?
 - Test street
 - General practitioner
 - Night/emergency center for general practice
 - Municipal medical assistance organisation
 - Regional medical assistance organisation
 - Hospital
 - Selftest
 - Commercial party
 - Do not know

Questions added to Survey 3.

- Did you get tested for Corona since the start of the pandemic (early 2020)?
 - Yes
 - No
 - I don't know
- How often were you tested since the start of the pandemic (early 2020)?
- How often was the test positive since the start of the pandemic (early 2020)?
- Was this a re-contamination?
 - Yes
 - No
 - I don't know
- When were you tested the first time and the test result was positive since the start of the pandemic (early 2020)?
- When were you tested the second time and the test result was positive since the start of the pandemic (early 2020)?
- When did you last tested positive since the start of the pandemic (early 2020)?

Questions regarding housemates

- How often was your housemate tested since the start of the pandemic (early 2020)?
- How often was the test positive since the start of the pandemic (early 2020)?
- Was this a re-contamination?
 - Yes
 - No
 - I don't know
- When did your housemate get tested and the test result was positive for the first time since the start of the pandemic (early 2020)?
- When did your housemate get tested the second time and the test result was positive since the start of the pandemic (early 2020)?
- When did your housemate get the last positive test since the start of the pandemic (early 2020)?