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df1

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## Changes to data when transforming *df1* into *df2*

All questions names are matched between the databases. All patients are matched between the databases. There are 12 366 changes to the values to the existing patients and existing questions between the databases, which is 103% of all non-missing values.

### Changes to the patient ANTA-0002

- cannot convert value No to number in 62 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)

- 1 added in 43 questions: *How many family members 1 had a history of ALS* (q\_100a\_2), *How many family members 2 had a history of ALS* (q\_100b\_2), *How many family members 3 had a history of ALS* (q\_100c\_2), *How many family members 1 had a history of FTD* (q\_101a\_2), *How many family members 2 had a history of FTD* (q\_101b\_2), *How many family members 3 had a history of FTD* (q\_101c\_2), *How many family members 1 had a history of Alzheimer disease* (q\_102a\_2), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 18 questions: q\_110d, q\_111, q\_123, q\_124, q\_125, q\_126, q\_127, ... q\_136, q\_137, q\_138
- cannot convert value **Yes** to number in 16 questions: q\_149d, q\_149h, q\_152h, q\_156h, q\_16b, q\_24c, q\_25d, ... q\_28b, q\_28c, q\_29a
- 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- factor variable q\_24, q\_26, q\_28, q\_30a and q\_99.c1 doesn't have defined level **Yes**
- **After** added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t), *5th timing* (q\_48e\_t) and *6th timing* (q\_48f\_t)
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), *Did specialist 1 made diagnosis* (q\_154d\_1) and *Did specialist 2 made diagnosis* (q\_154d\_2)
- NA removed in *Creatinine level (or NF, NA, NR)* (q\_55a), *Creatinine lower range* (q\_55b) and *Creatinine upper range* (q\_55c)
- Normal replaces value **Abnormal** in q\_60, q\_61 and q\_62
- Niece **maternal** added in *Which family member 1 had a history of ALS* (q\_100a\_1), *Which family member 1 had a history of FTD* (q\_101a\_1) and *Which family member 1 had a history of Alzheimer disease* (q\_102a\_1)
- Niece **paternal** added in *Which family member 2 had a history of ALS* (q\_100b\_1), *Which family member 2 had a history of FTD* (q\_101b\_1) and *Which family member 2 had a history of Alzheimer disease* (q\_102b\_1)
- Niece **unknown line** added in *Which family member 3 had a history of ALS* (q\_100c\_1), *Which family member 3 had a history of FTD* (q\_101c\_1) and *Which family member 3 had a history of Alzheimer disease* (q\_102c\_1)
- **Neurologist** added in *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153) and *What specialist 2 observed the patient* (q\_154b\_2)
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- 2 added in *Number of children* (q\_110a) and *Order of specialist 2 that observed the patient* (q\_154a\_2)
- cannot convert value **Urban area** to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)

- General Practitioner added in *First specialist who observed the patient* (q\_148) and *What specialist 1 observed the patient* (q\_154b\_1)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level *Caucassian*
- factor variable q\_16g doesn't have defined level *No*
- Lower limb replaces value Upper limb in *Limb onset* (q\_18a)
- Distal and proximal replaces value Proximal in *Predominant impairment* (q\_18c)
- 1 Oro-facial added in *1st region* (q\_48a\_r)
- 2b Right Upper limb - proximal added in *2nd region* (q\_48b\_r)
- 3b Left Upper limb - proximal added in *3rd region* (q\_48c\_r)
- 2a Right Upper limb - distal added in *4th region* (q\_48d\_r)
- 3a Left Upper limb - distal added in *5th region* (q\_48e\_r)
- 4b Right Lower limb - proximal added in *6th region* (q\_48f\_r)
- 2017-11-14 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value *Speech combined with nonvocal communication* to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value *Moderately excessive saliva; may have minimal drooling* to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2)
- cannot convert value *Dietary consistency changes* to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value *Slow or sloppy; all words are legible* to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value *Somewhat slow and clumsy, but no help needed* to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value *Total dependence* to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value *Helpless* to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value *Walks with assistance* to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value *Cannot do* to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- cannot convert value *Occurs with >= 1 of the following: eating, bathing, dressing (ADL)* to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10)
- cannot convert value *None* to number in *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11)
- cannot convert value *Intermittent use of BiPAP* to number in *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- No replaces value Yes in q\_63
- Wt/wt (normal) removed in q\_97a
- Father added in *Which family member 1 had died* (q\_106\_1a)

- Myocardial infarction added in *What cause of death of family member 1* (q\_106\_1b)
- 90 added in *Age of family member 1 at the moment of death* (q\_106\_1d)
- 5 added in *Mother's number of siblings* (q\_107b)
- 3 added in *Father's number of siblings* (q\_108b)
- "housewife" removed in *Main Occupation* (q\_139)
- "ANTA" removed in *centr\_id*

## Changes to the patient ANTA-0011

- cannot convert value No to number in 65 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 30 questions: *Mother's birth order* (q\_107a), *Siblings' birth order* (q\_110a1), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 15 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_135, q\_136, q\_138
- cannot convert value Yes to number in 13 questions: q\_149a, q\_152d, q\_152e, q\_152f, q\_152h, q\_156h, q\_16a, ... q\_28a, q\_28b, q\_28c
- 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- factor variable q\_137, q\_26, q\_28, q\_30a and q\_99.c1 doesn't have defined level Yes
- 2 added in *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - Normal* (q\_65a\_1), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)
- After added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t) and *5th timing* (q\_48e\_t)
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), *Did specialist 1 made diagnosis* (q\_154d\_1) and *Did specialist 2 made diagnosis* (q\_154d\_2)
- cannot convert value None to number in *ALSFRS(1) 10. Dyspnea*

- (q\_51\_1.10), *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- **Neurologist** added in *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153) and *What specialist 2 observed the patient* (q\_154b\_2)
  - factor variable **q\_16g** and **q\_24** doesn't have defined level **No**
  - **No** replaces value **Yes** in **q\_19** and **q\_63**
  - **NA** removed in *Total Cholesterol lower range* (q\_56b) and *Triglycerides lower range* (q\_59b)
  - *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged **NA 2**
  - **other** added in *What cause of death of family member 1* (q\_106\_1b) and *What cause of death of family member 2* (q\_106\_2b)
  - **"unknown"** added in *What other cause of death of family member 1* (q\_106\_1c) and *What other cause of death of family member 2* (q\_106\_2c)
  - **4** added in *Father's number of siblings* (q\_108b) and *Number of siblings* (q\_110a2)
  - cannot convert value **Rural area** to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
  - **Antalya** added in *Medical facility* (facility\_id)
  - **Hilmi Uysal** added in *Physician recording the data* (person\_id)
  - factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucassian**
  - **Upper and lower** replaces value **Lower limb** in *Limb onset* (q\_18a)
  - factor variable *Predominant impairment* (q\_18c) doesn't have defined level **Distal**
  - **4b Right Lower limb - proximal** added in *1st region* (q\_48a\_r)
  - **5b Left Lower limb - proximal** added in *2nd region* (q\_48b\_r)
  - **4a Right Lower limb - distal** added in *3rd region* (q\_48c\_r)
  - **5a Left Lower limb - distal** added in *4th region* (q\_48d\_r)
  - **1 Oro-facial** added in *5th region* (q\_48e\_r)
  - **Bulbar** replaces value **Cervical** in *Region2* (q\_49b)
  - **Bulbar** removed in *Region3* (q\_50a)
  - **2017-12-05** added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
  - cannot convert value **Normal speech processes** to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
  - cannot convert value **Normal** to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2)
  - cannot convert value **Normal eating habits** to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
  - cannot convert value **Not all words are legible** to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
  - cannot convert value **Can cut most foods, although clumsy and slow; some help needed** to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
  - cannot convert value **Total dependence** to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)

- cannot convert value **Can turn alone or adjust sheets, but with great difficulty** to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value **Nonambulatory functional movement** to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value **Needs assistance** to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- **Type II** replaces value **Type I** in q\_74
- **Yes** replaces value **No** in q\_91a
- 2014-01-01 replaces value 1905-07-06 in *Date of initiation of Riluzole* (q\_91b)
- **Wt/wt (normal)** removed in q\_97a
- **A** added in *Abnormal C9orf72 repeat-expansion* (q\_98\_1)
- **Mutation found** added in *TBK1 mutation* (q\_98\_2a)
- **Father** added in *Which family member 1 had died* (q\_106\_1a)
- **83** added in *Age of family member 1 at the moment of death* (q\_106\_1d)
- **Son** added in *Which family member 2 had died* (q\_106\_2a)
- **56** added in *Age of family member 2 at the moment of death* (q\_106\_2d)
- **9** added in *Mother's number of siblings* (q\_107b)
- **3** added in *Father's birth order* (q\_108a)
- **"housewife"** removed in *Main Occupation* (q\_139)
- **General Practitioner** added in *First specialist who observed the patient* (q\_148)
- cannot convert value NA to integer in *Time gap between first-second specialist* (q\_151)
- **Cardiologist** added in *What specialist 1 observed the patient* (q\_154b\_1)
- **"ANTA"** removed in **centr\_id**

## Changes to the patient ANTA-0015

- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- cannot convert value **No** to number in 57 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118c, q\_119a, q\_119b, ... q\_38.1b, q\_38.2a, q\_38.2b
- **1** added in 31 questions: *How many family members 1 had a history of ALS* (q\_100a\_2), *How many family members 1 had a history of Parkinson disease* (q\_103a\_2), *Mother's birth order* (q\_107a), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord*

*MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)

- cannot convert value **Yes** to number in 21 questions: q\_118b, q\_152d, q\_152e, q\_152f, q\_152h, q\_156h, q\_16a, ... q\_28c, q\_29a, q\_29b
- No removed in 18 questions: q\_123, q\_124, q\_125, q\_127, q\_128, q\_129, q\_130, ... q\_145, q\_146, q\_147
- 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- 2 added in *Siblings' birth order* (q\_110a1), *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - Tumor* (q\_65a\_2), *Spinal cord MRI Thoracic - Tumor* (q\_65b\_2) and *Spinal cord MRI Lumbo-sacral - Tumor* (q\_65c\_2)
- factor variable q\_24, q\_26, q\_28 and q\_99.c1 doesn't have defined level **Yes**
- **After** added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t) and *5th timing* (q\_48e\_t)
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116) and *Did specialist 1 made diagnosis* (q\_154d\_1)
- factor variable q\_16g and q\_30a doesn't have defined level **No**
- cannot convert value **None** to number in *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- **Country towns-** 1000-5 000 removed in *Place of living* (q\_143) and *Place of living* (q\_144)
- cannot convert value **Rural area** to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- NA removed in *Time gap between first-second specialist* (q\_151) and *Time gap between first medical observation and diagnosis* (q\_155)
- **Antalya** added in *Medical facility* (facility\_id)
- **Hilmi Uysal** added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucassian**
- **Upper and lower** replaces value **Lower limb** in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level **Distal**
- **4a Right Lower limb - distal** added in *1st region* (q\_48a\_r)
- **2a Right Upper limb - distal** added in *2nd region* (q\_48b\_r)
- **5a Left Lower limb - distal** added in *3rd region* (q\_48c\_r)
- **3a Left Upper limb - distal** added in *4th region* (q\_48d\_r)
- **1 Oro-facial** added in *5th region* (q\_48e\_r)
- **2017-12-20** added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value **Loss of useful speech** to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)



- cannot convert value `Normal` to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2)
- cannot convert value `Dietary consistency changes` to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value `Unable to grip pen` to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value `Needs to be fed` to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value `Total dependence` to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value `Helpless` to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value `No purposeful leg movement` to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value `Cannot do` to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- cannot convert value `Occurs with >= 1 of the following: eating, bathing, dressing (ADL)` to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- No replaces value `Yes` in q\_63
- 2014-01-01 replaces value 1905-07-06 in *Date of initiation of Riluzole* (q\_91b)
- Mutation found removed in q\_97a
- "SNP" removed in *SOD1 mutation type* (q\_97b)
- Sister added in *Which family member 1 had a history of ALS* (q\_100a\_1)
- Uncle maternal added in *Which family member 1 had a history of Parkinson disease* (q\_103a\_1)
- Father added in *Which family member 1 had died* (q\_106\_1a)
- other added in *What cause of death of family member 1* (q\_106\_1b)
- "UNKNOWN" added in *What other cause of death of family member 1* (q\_106\_1c)
- 60 added in *Age of family member 1 at the moment of death* (q\_106\_1d)
- 6 added in *Mother's number of siblings* (q\_107b)
- 3 added in *Father's birth order* (q\_108a)
- 7 added in *Father's number of siblings* (q\_108b)
- 9 added in *Number of siblings* (q\_110a2)
- "officer" removed in *Main Occupation* (q\_139)
- "farmer" removed in *Second Occupation* (q\_141)
- Rehabilitation specialist added in *What specialist 1 observed the patient* (q\_154b\_1)
- Neurologist added in *What specialist 2 observed the patient* (q\_154b\_2)
- Yes added in *Did specialist 2 made diagnosis* (q\_154d\_2)
- "ANTA" removed in *centr\_id*

## Changes to the patient ANTA-0016

- cannot convert value No to number in 71 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 29 questions: *Mother's birth order* (q\_107a), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), *Brain MRI - Hypoxia* (q\_64\_6), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 19 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_145, q\_146, q\_147
- cannot convert value Yes to number in q\_149a, q\_156h, q\_16a, q\_26a, q\_27a, q\_28a and q\_28b
- After added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t), *5th timing* (q\_48e\_t), *6th timing* (q\_48f\_t), *7th timing* (q\_48g\_t) and *8th timing* (q\_48h\_t)
- 2 added in *Number of children* (q\_110a), *Siblings' birth order* (q\_110a1), *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - Tumor* (q\_65a\_2), *Spinal cord MRI Thoracic - Tumor* (q\_65b\_2) and *Spinal cord MRI Lumbo-sacral - Tumor* (q\_65c\_2)
- 0 added in *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- factor variable q\_26, q\_28, q\_30a and q\_99.c1 doesn't have defined level Yes
- cannot convert value None to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10), *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116) and *Did specialist 1 made diagnosis* (q\_154d\_1)
- **Neurologist** added in *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153) and *What specialist 2 observed the patient* (q\_154b\_2)
- factor variable q\_16g and q\_24 doesn't have defined level No
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking*

- (q\_88d) doesn't allow for tagged NA 2
- cannot convert value **Rural area** to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- Internal Medicine** added in *First specialist who observed the patient* (q\_148) and *What specialist 1 observed the patient* (q\_154b\_1)
- Antalya** added in *Medical facility* (facility\_id)
- Hilmi Uysal** added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucassian**
- Lower limb** replaces value **Upper limb** in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level **Distal**
- 3a Left Upper limb - distal** added in *1st region* (q\_48a\_r)
- 2a Right Upper limb - distal** added in *2nd region* (q\_48b\_r)
- 3b Left Upper limb - proximal** added in *3rd region* (q\_48c\_r)
- 2b Right Upper limb - proximal** added in *4th region* (q\_48d\_r)
- 7 Neck** added in *5th region* (q\_48e\_r)
- 5b Left Lower limb - proximal** added in *6th region* (q\_48f\_r)
- 4b Right Lower limb - proximal** added in *7th region* (q\_48g\_r)
- 1 Oro-facial** added in *8th region* (q\_48h\_r)
- 2018-01-11** added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value **Detectable speech disturbances** to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value **Normal** to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2)
- cannot convert value **Normal eating habits** to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value **Unable to grip pen** to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value **Needs to be fed** to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value **Total dependence** to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value **Can turn alone or adjust sheets, but with great difficulty** to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value **Early ambulation difficulties** to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value **Mild unsteadiness or fatigue** to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- NA** replaces value **NA** in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- No** replaces value **Yes** in q\_63
- 2014-01-01** replaces value **1905-07-06** in *Date of initiation of Riluzole* (q\_91b)
- Wt/wt (normal)** removed in q\_97a
- Father** added in *Which family member 1 had died* (q\_106\_1a)
- other** added in *What cause of death of family member 1* (q\_106\_1b)

- "SVA" added in *What other cause of death of family member 1* (q\_106\_1c)
- 70 added in *Age of family member 1 at the moment of death* (q\_106\_1d)
- 7 added in *Mother's number of siblings* (q\_107b)
- 4 added in *Father's birth order* (q\_108a)
- 12 added in *Father's number of siblings* (q\_108b)
- 5 added in *Number of siblings* (q\_110a2)
- "farmer" removed in *Main Occupation* (q\_139)
- Yes added in *Did specialist 2 made diagnosis* (q\_154d\_2)
- "ANTA" removed in `centr_id`

## Changes to the patient ANTA-0017

- cannot convert value No to number in 65 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 28 questions: *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Tumor* (q\_64\_2), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), *Brain MRI - Hypoxia* (q\_64\_6), *Brain MRI - NA* (q\_64\_7), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 16 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_136, q\_137, q\_138
- cannot convert value Yes to number in 13 questions: q\_149b, q\_152d, q\_152e, q\_152h, q\_156h, q\_16a, q\_16c, ... q\_28a, q\_29a, q\_29b
- 2 added in *Mother's birth order* (q\_107a), *Father's birth order* (q\_108a), *Father's number of siblings* (q\_108b), *Siblings' birth order* (q\_110a1), *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Normal* (q\_64\_1), *Spinal cord MRI Cervical - Normal* (q\_65a\_1), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)
- 0 added in *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- After added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t), *5th timing* (q\_48e\_t), *6th timing* (q\_48f\_t) and *8th timing* (q\_48h\_t)
- factor variable q\_26, q\_28, q\_30a, q\_87a and q\_99.c1 doesn't have defined level Yes

- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), *Did specialist 1 made diagnosis* (q\_154d\_1) and *Did specialist 2 made diagnosis* (q\_154d\_2)
- **Neurologist** added in *First specialist who observed the patient* (q\_148), *Second specialist who observed the patient* (q\_150), *What specialist 1 observed the patient* (q\_154b\_1) and *What specialist 2 observed the patient* (q\_154b\_2)
- cannot convert value **Normal** to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2), *ALSFRS(1) 4. Handwriting* (q\_51\_1.4) and *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- factor variable q\_16g and q\_24 doesn't have defined level **No**
- cannot convert value **None** to number in *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- **Antalya** added in *Medical facility* (facility\_id)
- **Hilmi Uysal** added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucassian**
- **Lower limb** replaces value **Upper limb** in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level **Distal**
- **2a Right Upper limb - distal** added in *1st region* (q\_48a\_r)
- **2b Right Upper limb - proximal** added in *2nd region* (q\_48b\_r)
- **3b Left Upper limb - proximal** added in *3rd region* (q\_48c\_r)
- **3a Left Upper limb - distal** added in *4th region* (q\_48d\_r)
- **5a Left Lower limb - distal** added in *5th region* (q\_48e\_r)
- **4a Right Lower limb - distal** added in *6th region* (q\_48f\_r)
- **6 Respiratory symptoms** added in *7th region* (q\_48g\_r)
- **Same time** added in *7th timing* (q\_48g\_t)
- **1 Oro-facial** added in *8th region* (q\_48h\_r)
- **Thoracic** replaces value **Bulbar** in *Region3* (q\_50a)
- **2018-01-11** added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value **Normal speech processes** to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value **Early eating problems - occasional choking** to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value **Needs attendant for self-care** to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value **Can initiate, but not turn or adjust sheets alone** to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value **Walks with assistance** to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value **Cannot do** to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- cannot convert value **Occurs when walking** to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10)
- **NA** replaces value **NA** in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)

- No replaces value Yes in q\_63
- 1976 replaces value NA in *Year of initiation of smoking* (q\_88b)
- *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- 2014-01-01 replaces value 1905-07-06 in *Date of initiation of Riluzole* (q\_91b)
- Mutation found removed in q\_97a
- "SNP" removed in *SOD1 mutation type* (q\_97b)
- Father added in *Which family member 1 had died* (q\_106\_1a)
- other added in *What cause of death of family member 1* (q\_106\_1b)
- "CVA" added in *What other cause of death of family member 1* (q\_106\_1c)
- 86 added in *Age of family member 1 at the moment of death* (q\_106\_1d)
- 4 added in *Mother's number of siblings* (q\_107b)
- 6 added in *Number of siblings* (q\_110a2)
- "shepherd" removed in *Main Occupation* (q\_139)
- cannot convert value Rural area to number in *Lives in Rural Area/Urban* (q\_143a)
- cannot convert value Urban area to number in *Lives in Rural Area/Urban* (q\_144a)
- "ANTA" removed in centr\_id

## Changes to the patient ANTA-0018

- cannot convert value No to number in 65 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 28 questions: *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Tumor* (q\_64\_2), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Trauma* (q\_64\_5), *Brain MRI - Hypoxia* (q\_64\_6), *Brain MRI - NA* (q\_64\_7), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 14 questions: q\_124, q\_125, q\_126, q\_127, q\_129, q\_130, q\_131, ... q\_136, q\_137, q\_138
- cannot convert value Yes to number in 13 questions: q\_149g, q\_152e, q\_152g, q\_152h, q\_156d, q\_156h, q\_16a, ... q\_29a, q\_29b, q\_29c
- 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)

- 2 added in *Mother's birth order* (q\_107a), *Father's birth order* (q\_108a), *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Spinal cord MRI Cervical - Normal* (q\_65a\_1), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)
- After added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t), *5th timing* (q\_48e\_t), *6th timing* (q\_48f\_t) and *7th timing* (q\_48g\_t)
- factor variable q\_123, q\_128, q\_26, q\_28 and q\_99.c1 doesn't have defined level Yes
- Neurologist added in *First specialist who observed the patient* (q\_148), *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153), *What specialist 1 observed the patient* (q\_154b\_1) and *What specialist 2 observed the patient* (q\_154b\_2)
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), *Did specialist 1 made diagnosis* (q\_154d\_1) and *Did specialist 2 made diagnosis* (q\_154d\_2)
- factor variable q\_16g, q\_24 and q\_30a doesn't have defined level No
- cannot convert value Normal to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2), *ALSFRS(1) 4. Handwriting* (q\_51\_1.4) and *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value None to number in *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- NA removed in *LDL Cholesterol lower range* (q\_58b) and *Triglycerides lower range* (q\_59b)
- Year of initiation of smoking (q\_88b) and Year of interruption of smoking (q\_88d) doesn't allow for tagged NA 2
- other added in *What cause of death of family member 1* (q\_106\_1b) and *What cause of death of family member 2* (q\_106\_2b)
- "Unknown" added in *What other cause of death of family member 1* (q\_106\_1c) and *What other cause of death of family member 2* (q\_106\_2c)
- 3 added in *Mother's number of siblings* (q\_107b) and *Father's number of siblings* (q\_108b)
- cannot convert value Rural area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- "ANTC0009" added in *Control subject code* (q\_3b)
- factor variable Ethnicity (q\_7) doesn't have defined level Caucassian
- Upper and lower replaces value Lower limb in *Limb onset* (q\_18a)
- factor variable Predominant impairment (q\_18c) doesn't have defined level Distal
- 4a Right Lower limb - distal added in *1st region* (q\_48a\_r)
- 4b Right Lower limb - proximal added in *2nd region* (q\_48b\_r)
- 5a Left Lower limb - distal added in *3rd region* (q\_48c\_r)
- 5b Left Lower limb - proximal added in *4th region* (q\_48d\_r)

- 2a Right Upper limb - distal added in *5th region* (q\_48e\_r)
- 3a Left Upper limb - distal added in *6th region* (q\_48f\_r)
- 1 Oro-facial added in *7th region* (q\_48g\_r)
- 2018-01-11 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value Normal speech processes to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value Normal eating habits to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value Normal function to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value Helpless to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value No purposeful leg movement to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value Cannot do to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- cannot convert value Significant difficulty, considering using mechanical respiratory support to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- No replaces value Yes in q\_63
- Type II replaces value Type I in q\_74
- 2014-01-01 replaces value 1905-07-06 in *Date of initiation of Riluzole* (q\_91b)
- Mutation found removed in q\_97a
- "SNP" removed in *SOD1 mutation type* (q\_97b)
- Father added in *Which family member 1 had died* (q\_106\_1a)
- 58 added in *Age of family member 1 at the moment of death* (q\_106\_1d)
- Son added in *Which family member 2 had died* (q\_106\_2a)
- 53 added in *Age of family member 2 at the moment of death* (q\_106\_2d)
- 5 added in *Number of children* (q\_110a)
- 6 added in *Siblings' birth order* (q\_110a1)
- 9 added in *Number of siblings* (q\_110a2)
- "farmer" removed in *Main Occupation* (q\_139)
- "ANTA" removed in centr\_id

## Changes to the patient ANTA-0022

- cannot convert value No to number in 71 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7),



- Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 29 questions: *Mother's birth order* (q\_107a), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), *Brain MRI - Hypoxia* (q\_64\_6), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
  - No removed in 13 questions: q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, q\_130, ... q\_135, q\_136, q\_138
  - cannot convert value **Yes** to number in q\_121a, q\_121b, q\_16b, q\_24a, q\_24c, q\_25a and q\_26a
  - factor variable q\_123, q\_132, q\_137, q\_24, q\_26, q\_30a and q\_99.c1 doesn't have defined level **Yes**
  - 2 added in *Mother's number of siblings* (q\_107b), *Father's birth order* (q\_108a), *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - Normal* (q\_65a\_1), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)
  - 0 added in *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
  - **After** added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t), *5th timing* (q\_48e\_t) and *6th timing* (q\_48f\_t)
  - No added in *Head/Neck trauma in the last 5 years* (q\_115), *Did specialist 1 made diagnosis* (q\_154d\_1) and *Did specialist 2 made diagnosis* (q\_154d\_2)
  - **Neurologist** added in *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153) and *What specialist 2 observed the patient* (q\_154b\_2)
  - factor variable q\_16g and q\_28 doesn't have defined level **No**
  - cannot convert value **Urban area** to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
  - **General Practitioner** added in *First specialist who observed the patient* (q\_148) and *What specialist 1 observed the patient* (q\_154b\_1)
  - **Antalya** added in *Medical facility* (facility\_id)
  - **Hilmi Uysal** added in *Physician recording the data* (person\_id)
  - factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucasian**
  - **Lower limb** replaces value **Upper limb** in *Limb onset* (q\_18a)
  - factor variable *Predominant impairment* (q\_18c) doesn't have defined level **Distal**
  - 1 **Oro-facial** added in *1st region* (q\_48a\_r)
  - 3a **Left Upper limb - distal** added in *2nd region* (q\_48b\_r)
  - 3b **Left Upper limb - proximal** added in *3rd region* (q\_48c\_r)
  - 5a **Left Lower limb - distal** added in *4th region* (q\_48d\_r)
  - 2a **Right Upper limb - distal** added in *5th region* (q\_48e\_r)

- 4a Right Lower limb - distal added in 6th region (q\_48f\_r)
- 2016-03-11 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value Detectable speech disturbances to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value Slight but definite excess of saliva in mouth; may have nighttime drooling to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2)
- cannot convert value Dietary consistency changes to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value Unable to grip pen to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value Needs to be fed to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value Total dependence to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value Helpless to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value No purposeful leg movement to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value Cannot do to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- cannot convert value Significant difficulty, considering using mechanical respiratory support to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10)
- cannot convert value Needs extra pillows in order to sleep (>2) to number in *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11)
- cannot convert value Intermittent use of BiPAP to number in *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- No replaces value Yes in q\_63
- 2005 replaces value NA in *Year of initiation of smoking* (q\_88b)
- *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- Yes replaces value No in q\_89a
- "Lithium" added in *Drug(s) used in psychiatric medication* (q\_89b)
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- "Gabapentine" replaces value "gabapentine" in *Antiepileptic's name* (q\_92b)
- Wt/wt (normal) removed in q\_97a
- Son added in *Which family member 1 had died* (q\_106\_1a)
- other added in *What cause of death of family member 1* (q\_106\_1b)
- "Unknown" added in *What other cause of death of family member 1* (q\_106\_1c)
- 60 added in *Age of family member 1 at the moment of death* (q\_106\_1d)
- 9 added in *Father's number of siblings* (q\_108b)
- 7 added in *Siblings' birth order* (q\_110a1)
- 8 added in *Number of siblings* (q\_110a2)

- Head added in *Head/Neck trauma > 5 years* (q\_116)
- "tourism" removed in *Main Occupation* (q\_139)
- "ANTA" removed in *centr\_id*

## Changes to the patient JENA0044

- cannot convert value No to number in 62 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 31 questions: *Father's birth order* (q\_108a), *Father's number of siblings* (q\_108b), *Siblings' birth order* (q\_110a1), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Tumor* (q\_64\_2), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- cannot convert value Yes to number in 16 questions: q\_122b, q\_156a, q\_156b, q\_156c, q\_156d, q\_156e, q\_156f, ... q\_27a, q\_28c, q\_29a
- 2 added in *Number of siblings* (q\_110a2), *How long vigorous sport activity 1* (q\_112b\_1c), *How long vigorous sport activity 2* (q\_112b\_2c), *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Normal* (q\_64\_1), *Spinal cord MRI Cervical - Normal* (q\_65a\_1), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)
- 0 added in *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- mmol/l added in *Total Cholesterol unit* (q\_56d), *HDL Cholesterol unit* (q\_57d), *LDL Cholesterol unit* (q\_58d) and *Triglycerides unit* (q\_59d)
- No removed in q\_110d, q\_145, q\_146 and q\_147
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), *Did specialist 1 made diagnosis* (q\_154d\_1) and *Did specialist 2 made diagnosis* (q\_154d\_2)
- Neurologist added in *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153), *What specialist 2 observed the patient* (q\_154b\_2) and *What specialist 3 observed the patient* (q\_154b\_3)
- Same time added in *2nd timing* (q\_48b\_t), *4th timing* (q\_48d\_t) and *6th timing* (q\_48f\_t)

- After added in *3rd timing* (q\_48c\_t), *5th timing* (q\_48e\_t) and *7th timing* (q\_48g\_t)
- "No" removed in *Second Occupation* (q\_141), *Second Occupation* (q\_142) and *Side effects of Riluzole* (q\_91c)
- cannot convert value None to number in *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- 4 added in *Mother's birth order* (q\_107a) and *Mother's number of siblings* (q\_107b)
- 3 added in *Number of children* (q\_110a) and *Order of specialist 3 that observed the patient* (q\_154a\_3)
- "heating engineer" removed in *Main Occupation* (q\_139) and *Main Occupation* (q\_140)
- cannot convert value Urban area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- Orthopaedist added in *First specialist who observed the patient* (q\_148) and *What specialist 1 observed the patient* (q\_154b\_1)
- Jena added in *Medical facility* (facility\_id)
- B Stubbendorf added in *Physician recording the data* (person\_id)
- Not related added in q\_3a
- factor variable *Ethnicity* (q\_7) doesn't have defined level *Caucassian*
- factor variable q\_16g doesn't have defined level No
- Upper and lower replaces value Lower limb in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level Distal
- Upper Limbs replaces value No in *Sensory changes* (q\_39)
- Positive added in q\_43
- 4a Right Lower limb - distal added in *1st region* (q\_48a\_r)
- 5a Left Lower limb - distal added in *2nd region* (q\_48b\_r)
- 4b Right Lower limb - proximal added in *3rd region* (q\_48c\_r)
- 5b Left Lower limb - proximal added in *4th region* (q\_48d\_r)
- 2a Right Upper limb - distal added in *5th region* (q\_48e\_r)
- 3a Left Upper limb - distal added in *6th region* (q\_48f\_r)
- 1 Oro-facial added in *7th region* (q\_48g\_r)
- 2017-05-04 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value Detectable speech disturbances to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value Normal to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2)
- cannot convert value Normal eating habits to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value Slow or sloppy; all words are legible to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value Can cut most foods, although clumsy and slow; some help needed to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value Independent and complete self-care with

- effort of decreased efficiency to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value *Somewhat slow and clumsy, but no help needed* to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value *Walks with assistance* to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value *Needs assistance* to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- cannot convert value *Occurs with >= 1 of the following: eating, bathing, dressing (ADL)* to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- $\mu\text{mol/l}\cdot\text{s}$  added in *CK unit* (q\_53d)
- g/l added in *Albumin unit* (q\_54d)
- $\mu\text{mol/l}$  added in *Creatinine unit* (q\_55d)
- "Budesonid" replaces value "Budesonid Spray" in *Steroid's name* (q\_95b)
- Wt/wt (normal) added in q\_97a
- A added in *Abnormal C9orf72 repeat-expansion* (q\_98\_1)
- factor variable q\_99.c1 doesn't have defined level Yes
- No replaces value Yes in q\_111
- Cycling added in *Type of vigorous sport activity 1* (q\_112b\_1a)
- Football added in *Type of vigorous sport activity 2* (q\_112b\_2a)
- cannot convert value NA to integer in *Time gap between first-second specialist* (q\_151)
- Yes added in *Did specialist 3 made diagnosis* (q\_154d\_3)
- "JENA" removed in *centr\_id*
- 105 replaces value 286 in x

## Changes to the patient ANTA-0001

- cannot convert value No to number in 68 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 39 questions: *Mother's birth order* (q\_107a), *Mother's number of siblings* (q\_107b), *Father's birth order* (q\_108a), *Father's number of siblings* (q\_108b), *Number of children* (q\_110a), *Siblings' birth order* (q\_110a1), *Number of siblings* (q\_110a2), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other*

- (q\_65c\_7), *Spinal cord MRI Lumbo-sacral* - NA (q\_65c\_8)
- NA removed in 26 questions: *Time gap between first-second specialist* (q\_151), *CK level (or NF, NA, NR)* (q\_53a), *CK lower range* (q\_53b), *CK upper range* (q\_53c), *Albumin level (or NF, NA, NR)* (q\_54a), *Albumin lower range* (q\_54b), *Albumin upper range* (q\_54c), ... *VC (% predicted values)* (q\_67), *SNIP – absolute value (cmH2O)* (q\_70), *Nocturnal oximetry – mean value (%)* (q\_71)
  - No removed in 20 questions: q\_110d, q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, ... q\_145, q\_146, q\_147
  - cannot convert value Yes to number in q\_149c, q\_152e, q\_152h, q\_156h, q\_16a, q\_26a, q\_27a, q\_29a, q\_29b and q\_29c
  - 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
  - factor variable q\_26, q\_28, q\_30a and q\_99.c1 doesn't have defined level Yes
  - After added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t) and *5th timing* (q\_48e\_t)
  - No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), *Did specialist 1 made diagnosis* (q\_154d\_1) and *Did specialist 2 made diagnosis* (q\_154d\_2)
  - factor variable q\_16g and q\_24 doesn't have defined level No
  - cannot convert value None to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10) and *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11)
  - Normal replaces value Abnormal in q\_61 and q\_62
  - *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
  - Large town- > 100 000 removed in *Place of living* (q\_143) and *Place of living* (q\_144)
  - cannot convert value Urban area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
  - Neurologist added in *What specialist 1 observed the patient* (q\_154b\_1) and *What specialist 2 observed the patient* (q\_154b\_2)
  - Antalya added in *Medical facility* (facility\_id)
  - Hilmi Uysal added in *Physician recording the data* (person\_id)
  - factor variable *Ethnicity* (q\_7) doesn't have defined level Caucassian
  - 2015-12-01 removed in *Date of Invasive ventilation* (q\_14)
  - Upper and lower replaces value Lower limb in *Limb onset* (q\_18a)
  - factor variable *Predominant impairment* (q\_18c) doesn't have defined level Distal
  - 5a Left Lower limb – distal added in *1st region* (q\_48a\_r)
  - 4a Right Lower limb – distal added in *2nd region* (q\_48b\_r)
  - 2a Right Upper limb – distal added in *3rd region* (q\_48c\_r)
  - 3a Left Upper limb – distal added in *4th region* (q\_48d\_r)

- 7 Neck added in *5th region* (q\_48e\_r)
- Lumbo-sacral replaces value Cervical in *Region1* (q\_49a)
- Cervical replaces value Lumbo-sacral in *Region2* (q\_49b)
- Bulbar replaces value Thoracic in *Region3* (q\_50a)
- 2017-10-28 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value Detectable speech disturbances to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value Normal to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2)
- cannot convert value Normal eating habits to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value Unable to grip pen to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value Needs to be fed to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value Total dependence to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value Helpless to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value No purposeful leg movement to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value Cannot do to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- cannot convert value Invasive mechanical ventilation by intubation or tracheostomy to number in *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- No replaces value Yes in q\_63
- 2013-01-01 replaces value 1905-07-05 in *Date of initiation of Riluzole* (q\_91b)
- Wt/wt (normal) removed in q\_97a
- "marketing staff" removed in *Main Occupation* (q\_139)
- "business manger" removed in *Main Occupation* (q\_140)
- 2 added in *Order of specialist 2 that observed the patient* (q\_154a\_2)
- "ANTA" removed in centr\_id

## Changes to the patient ANTA-0003

- NA added in 90 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)

- cannot convert value **No** to number in 67 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- **No** removed in 17 questions: q\_111, q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, ... q\_136, q\_137, q\_138
- cannot convert value **Yes** to number in 11 questions: q\_152d, q\_152h, q\_16a, q\_26a, q\_26b, q\_26c, q\_27a, ... q\_28b, q\_28c, q\_29a
- 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- factor variable q\_26, q\_28, q\_30a and q\_99.c1 doesn't have defined level **Yes**
- **After** added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t) and *5th timing* (q\_48e\_t)
- **NA** removed in *Creatinine level (or NF, NA, NR)* (q\_55a), *Creatinine lower range* (q\_55b), *Creatinine upper range* (q\_55c) and *SNIP - absolute value (cmH2O)* (q\_70)
- 3 added in *Father's birth order* (q\_108a), *Father's number of siblings* (q\_108b), *Number of children* (q\_110a) and *Siblings' birth order* (q\_110a1)
- **No** added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), *Did specialist 1 made diagnosis* (q\_154d\_1) and *Did specialist 2 made diagnosis* (q\_154d\_2)
- cannot convert value **None** to number in *ALSFERS(1) 10. Dyspnea* (q\_51\_1.10), *ALSFERS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFERS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- **Neurologist** added in *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153) and *What specialist 2 observed the patient* (q\_154b\_2)
- factor variable q\_16g and q\_24 doesn't have defined level **No**
- **Abnormal** removed in q\_61 and q\_62
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged **NA** 2
- 1 added in *Mother's birth order* (q\_107a) and *Order of specialist 1 that observed the patient* (q\_154a\_1)
- 2 added in *Mother's number of siblings* (q\_107b) and *Order of specialist 2 that observed the patient* (q\_154a\_2)
- **Large town- > 100 000** added in *Place of living* (q\_143) and *Place of living* (q\_144)
- cannot convert value **Urban area** to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- **Internal Medicine** added in *First specialist who observed the patient* (q\_148) and *What specialist 1 observed the patient* (q\_154b\_1)
- **Antalya** added in *Medical facility* (facility\_id)
- **Hilmi Uysal** added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucassian**



- Lower limb replaces value Upper limb in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level Distal
- 3a Left Upper limb - distal added in *1st region* (q\_48a\_r)
- 2a Right Upper limb - distal added in *2nd region* (q\_48b\_r)
- 5a Left Lower limb - distal added in *3rd region* (q\_48c\_r)
- 4a Right Lower limb - distal added in *4th region* (q\_48d\_r)
- 7 Neck added in *5th region* (q\_48e\_r)
- 2017-11-14 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value Loss of useful speech to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value Marked excess of saliva with some drooling to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2)
- cannot convert value Needs supplemental tube feeding to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value Unable to grip pen to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value Needs to be fed to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value Total dependence to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value Helpless to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value No purposeful leg movement to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value Cannot do to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- Normal removed in q\_60
- No replaces value Yes in q\_63
- 2007-01-01 replaces value 1905-06-29 in *Date of initiation of Riluzole* (q\_91b)
- Wt/wt (normal) removed in q\_97a
- 7 added in *Number of siblings* (q\_110a2)
- "farmer" removed in *Main Occupation* (q\_139)
- "ANTA" removed in *centr\_id*

## Changes to the patient ANTA-0004

- cannot convert value No to number in 59 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular*

- specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 29 questions: *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), *Brain MRI - Hypoxia* (q\_64\_6), *Brain MRI - NA* (q\_64\_7), ... *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8), *Mean number of packs/day* (q\_88e)
- cannot convert value Yes to number in 19 questions: q\_149d, q\_149e, q\_149h, q\_156d, q\_156e, q\_156h, q\_16a, ... q\_28a, q\_28b, q\_28c
- No removed in 18 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_145, q\_146, q\_147
- 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b) and *ALS depression inventory lower range* (q\_47c)
- 2 added in *Number of children* (q\_110a), *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - Tumor* (q\_65a\_2), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)
- factor variable q\_133, q\_24, q\_26, q\_28 and q\_99.c1 doesn't have defined level Yes
- mg/dl added in *Creatinine unit* (q\_55d), *Total Cholesterol unit* (q\_56d), *HDL Cholesterol unit* (q\_57d), *LDL Cholesterol unit* (q\_58d) and *Triglycerides unit* (q\_59d)
- Neurologist added in *First specialist who observed the patient* (q\_148), *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153), *What specialist 1 observed the patient* (q\_154b\_1) and *What specialist 2 observed the patient* (q\_154b\_2)
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), *Did specialist 1 made diagnosis* (q\_154d\_1) and *Did specialist 2 made diagnosis* (q\_154d\_2)
- After added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t) and *4th timing* (q\_48d\_t)
- 3 added in *Father's birth order* (q\_108a), *Father's number of siblings* (q\_108b) and *Siblings' birth order* (q\_110a1)
- factor variable q\_16g and q\_30a doesn't have defined level No
- 4 added in *Mother's birth order* (q\_107a) and *Mother's number of siblings* (q\_107b)
- "carpenter" removed in *Main Occupation* (q\_139) and *Second Occupation* (q\_141)
- cannot convert value Urban area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)

- factor variable *Ethnicity* (q\_7) doesn't have defined level *Caucassian*
- 2017-10-01 removed in *Date of Death* (q\_15)
- *Lower limb* replaces value *Upper limb* in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level *Distal*
- 3a Left Upper limb - distal added in *1st region* (q\_48a\_r)
- 3b Left Upper limb - proximal added in *2nd region* (q\_48b\_r)
- 2b Right Upper limb - proximal added in *3rd region* (q\_48c\_r)
- 4a Right Lower limb - distal added in *4th region* (q\_48d\_r)
- *Lumbo-sacral* removed in *Region3* (q\_50a)
- 2017-11-22 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value *Speech combined with nonvocal communication* to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value *Normal* to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2)
- cannot convert value *Needs supplemental tube feeding* to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value *Unable to grip pen* to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value *Needs to be fed* to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value *Total dependence* to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value *Helpless* to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value *Nonambulatory functional movement* to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value *Cannot do* to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- cannot convert value *Occurs with >= 1 of the following: eating, bathing, dressing (ADL)* to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10)
- cannot convert value *Needs extra pillows in order to sleep (>2)* to number in *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11)
- cannot convert value *None* to number in *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- U/l added in *CK unit* (q\_53d)
- g/dl added in *Albumin unit* (q\_54d)
- No replaces value *Yes* in q\_63
- 2014 replaces value *NA* in *Year of initiation of smoking* (q\_88b)
- *Year of interruption of smoking* (q\_88d) doesn't allow for tagged *NA 2*
- 2016-01-01 replaces value 1905-07-08 in *Date of initiation of Riluzole* (q\_91b)
- *Wt/wt (normal)* removed in q\_97a
- 6 added in *Number of siblings* (q\_110a2)
- *Yes* removed in q\_111

- "ANTA" removed in `centr_id`

## Changes to the patient ANTA-0005

- cannot convert value No to number in 73 questions: `q_117a`, `q_117b`, `q_117c`, `q_118a`, `q_118b`, `q_118c`, `q_119a`, ... `q_38.1b`, `q_38.2a`, `q_38.2b`
- NA added in 59 questions: *Regular specific diet - No* (`q_114a`), *Regular specific diet - Mediterranean* (`q_114b`), *Regular specific diet - Vegetarian* (`q_114c`), *Regular specific diet - Vegan* (`q_114d`), *Regular specific diet - Gluten-free* (`q_114e`), *Regular specific diet - High protein* (`q_114f`), *Regular specific diet - Low carbohydrate* (`q_114g`), ... *Metastasis - Colon* (`q_85b_7`), *Metastasis - Rectum* (`q_85b_8`), *Metastasis - other Abdominal* (`q_85b_9`)
- 1 added in 29 questions: *Siblings' birth order* (`q_110a1`), *Order of specialist 1 that observed the patient* (`q_154a_1`), *Brain MRI - Normal* (`q_64_1`), *Brain MRI - Stroke* (`q_64_3`), *Brain MRI - Multiple Sclerosis* (`q_64_4`), *Brain MRI - Trauma* (`q_64_5`), *Brain MRI - Hypoxia* (`q_64_6`), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (`q_65c_6`), *Spinal cord MRI Lumbo-sacral - Other* (`q_65c_7`), *Spinal cord MRI Lumbo-sacral - NA* (`q_65c_8`)
- No removed in 14 questions: `q_123`, `q_124`, `q_125`, `q_126`, `q_127`, `q_128`, `q_129`, ... `q_135`, `q_136`, `q_138`
- 2 added in *How many family members 1 had a history of Alzheimer disease* (`q_102a_2`), *Number of siblings* (`q_110a2`), *Order of specialist 2 that observed the patient* (`q_154a_2`), *Brain MRI - Tumor* (`q_64_2`), *Spinal cord MRI Cervical - Tumor* (`q_65a_2`), *Spinal cord MRI Thoracic - Normal* (`q_65b_1`) and *Spinal cord MRI Lumbo-sacral - Normal* (`q_65c_1`)
- 0 added in *Cognition - ECAS lower range* (`q_45b`), *Cognition - ECAS upper range* (`q_45c`), *ALS depression inventory value (or NF, NA, NR)* (`q_47a`), *ALS depression inventory upper range* (`q_47b`), *ALS depression inventory lower range* (`q_47c`) and *Mean number of packs/day* (`q_88e`)
- After added in *2nd timing* (`q_48b_t`), *3rd timing* (`q_48c_t`), *4th timing* (`q_48d_t`), *5th timing* (`q_48e_t`), *6th timing* (`q_48f_t`) and *7th timing* (`q_48g_t`)
- Neurologist added in *First specialist who observed the patient* (`q_148`), *Second specialist who observed the patient* (`q_150`), *Specialist who made the diagnosis* (`q_153`), *What specialist 1 observed the patient* (`q_154b_1`), *What specialist 2 observed the patient* (`q_154b_2`) and *What specialist 3 observed the patient* (`q_154b_3`)
- cannot convert value Yes to number in `q_149e`, `q_156h`, `q_16a`, `q_27a` and `q_27b`
- factor variable `q_16g`, `q_24`, `q_28` and `q_30a` doesn't have defined level No
- factor variable `q_133`, `q_137`, `q_26` and `q_99.c1` doesn't have defined level Yes
- No added in *Head/Neck trauma in the last 5 years* (`q_115`), *Head/Neck trauma > 5 years* (`q_116`), *Did specialist 1 made diagnosis* (`q_154d_1`) and

*Did specialist 2 made diagnosis (q\_154d\_2)*

- cannot convert value **Normal** to number in *ALSFRS(1) 2. Salivation (q\_51\_1.2), ALSFRS(1) 8. Walking (q\_51\_1.8) and ALSFRS(1) 9. Climbing Stairs (q\_51\_1.9)*
- cannot convert value **None** to number in *ALSFRS(1) 10. Dyspnea (q\_51\_1.10), ALSFRS(1) 11. Orthopnea (q\_51\_1.11) and ALSFRS(1) 12. Respiratory insufficiency (q\_51\_1.12)*
- NA replaces value NA in *ALSFRS(1) Rate of decay (q\_51\_1.rate), HDL Cholesterol level (or NF, NA, NR) (q\_57a) and HDL Cholesterol lower range (q\_57b)*
- **3a Left Upper limb - distal** added in *1st region (q\_48a\_r) and 3rd region (q\_48c\_r)*
- **3b Left Upper limb - proximal** added in *2nd region (q\_48b\_r) and 4th region (q\_48d\_r)*
- cannot convert value **Somewhat slow and clumsy, but no help needed** to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils (q\_51\_1.5) and ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes (q\_51\_1.7)*
- **7** added in *Mother's number of siblings (q\_107b) and Father's number of siblings (q\_108b)*
- **3** added in *Father's birth order (q\_108a) and Order of specialist 3 that observed the patient (q\_154a\_3)*
- cannot convert value **Urban area** to number in *Lives in Rural Area/Urban (q\_143a) and Lives in Rural Area/Urban (q\_144a)*
- **Antalya** added in *Medical facility (facility\_id)*
- **Hilmi Uysal** added in *Physician recording the data (person\_id)*
- factor variable *Ethnicity (q\_7)* doesn't have defined level **Caucassian**
- **Lower limb** replaces value **Upper limb** in *Limb onset (q\_18a)*
- factor variable *Predominant impairment (q\_18c)* doesn't have defined level **Distal**
- **4a Right Lower limb - distal** added in *5th region (q\_48e\_r)*
- **5a Left Lower limb - distal** added in *6th region (q\_48f\_r)*
- **6 Respiratory symptoms** added in *7th region (q\_48g\_r)*
- factor variable *Region2 (q\_49b)* doesn't have defined level **Thoracic**
- **2017-11-22** added in *ALSFRS(1) Acquisition date (q\_51\_1.date)*
- cannot convert value **Normal speech processes** to number in *ALSFRS(1) 1. Speech (q\_51\_1.1)*
- cannot convert value **Normal eating habits** to number in *ALSFRS(1) 3. Swallowing (q\_51\_1.3)*
- cannot convert value **Slow or sloppy; all words are legible** to number in *ALSFRS(1) 4. Handwriting (q\_51\_1.4)*
- cannot convert value **Total dependence** to number in *ALSFRS(1) 6. Dressing and Hygiene (q\_51\_1.6)*
- **U/1** added in *CK unit (q\_53d)*
- **NA** removed in *LDL Cholesterol lower range (q\_58b)*
- **No** replaces value **Yes** in *q\_63*

- 1999 replaces value NA in *Year of initiation of smoking* (q\_88b)
- 2015 replaces value NA in *Year of interruption of smoking* (q\_88d)
- 2014-01-01 replaces value 1905-07-06 in *Date of initiation of Riluzole* (q\_91b)
- Wt/wt (normal) removed in q\_97a
- A added in *Abnormal C9orf72 repeat-expansion* (q\_98\_1)
- Aunt maternal added in *Which family member 1 had a history of Alzheimer disease* (q\_102a\_1)
- 5 added in *Mother's birth order* (q\_107a)
- "military officer" removed in *Main Occupation* (q\_139)
- "sergeant" removed in *Main Occupation* (q\_140)
- Yes added in *Did specialist 3 made diagnosis* (q\_154d\_3)
- "ANTA" removed in centr\_id

## Changes to the patient ANTA-0006

- cannot convert value No to number in 69 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 31 questions: *Mother's birth order* (q\_107a), *Father's birth order* (q\_108a), *Siblings' birth order* (q\_110a1), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 17 questions: q\_110d, q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, ... q\_136, q\_137, q\_138
- cannot convert value Yes to number in q\_149b, q\_149e, q\_149h, q\_152h, q\_156h, q\_16a, q\_26a, q\_27a and q\_28a
- 0 added in *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- After added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t), *5th timing* (q\_48e\_t), *6th timing* (q\_48f\_t) and *7th timing* (q\_48g\_t)
- 2 added in *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - Tumor* (q\_65a\_2), *Spinal cord MRI Thoracic - Tumor* (q\_65b\_2) and *Spinal cord MRI Lumbo-sacral - Tumor* (q\_65c\_2)

- Neurologist added in *First specialist who observed the patient* (q\_148), *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153), *What specialist 1 observed the patient* (q\_154b\_1) and *What specialist 2 observed the patient* (q\_154b\_2)
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), *Did specialist 1 made diagnosis* (q\_154d\_1) and *Did specialist 2 made diagnosis* (q\_154d\_2)
- factor variable q\_16g, q\_24 and q\_30a doesn't have defined level No
- factor variable q\_26, q\_28 and q\_99.c1 doesn't have defined level Yes
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- 3 added in *Mother's number of siblings* (q\_107b) and *Number of siblings* (q\_110a2)
- cannot convert value Urban area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level Caucasian
- Lower limb replaces value Upper limb in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level Distal
- 3a Left Upper limb - distal added in *1st region* (q\_48a\_r)
- 2a Right Upper limb - distal added in *2nd region* (q\_48b\_r)
- 3b Left Upper limb - proximal added in *3rd region* (q\_48c\_r)
- 2b Right Upper limb - proximal added in *4th region* (q\_48d\_r)
- 5a Left Lower limb - distal added in *5th region* (q\_48e\_r)
- 5b Left Lower limb - proximal added in *6th region* (q\_48f\_r)
- 6 Respiratory symptoms added in *7th region* (q\_48g\_r)
- Thoracic replaces value Bulbar in *Region3* (q\_50a)
- cannot convert value Normal speech processes to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value Normal to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2)
- cannot convert value Normal eating habits to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value Unable to grip pen to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value Needs to be fed to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value Total dependence to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value Helpless to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value Walks with assistance to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value Needs assistance to number in *ALSFRS(1) 9.*

*Climbing Stairs* (q\_51\_1.9)

- cannot convert value Occurs with  $\geq 1$  of the following: eating, bathing, dressing (ADL) to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10)
- cannot convert value Needs extra pillows in order to sleep ( $>2$ ) to number in *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11)
- cannot convert value None to number in *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- No replaces value Yes in q\_63
- 2014-01-01 replaces value 1905-07-06 in *Date of initiation of Riluzole* (q\_91b)
- Wt/wt (normal) removed in q\_97a
- 4 added in *Father's number of siblings* (q\_108b)
- "driver" removed in *Main Occupation* (q\_139)
- "repairman" removed in *Second Occupation* (q\_141)
- Large town-  $> 100\ 000$  added in *Place of living* (q\_143)
- "ANTA" removed in centr\_id

## Changes to the patient ANTA-0008

- cannot convert value No to number in 61 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 28 questions: *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), *Brain MRI - Hypoxia* (q\_64\_6), *Brain MRI - NA* (q\_64\_7), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- cannot convert value Yes to number in 17 questions: q\_122a, q\_149a, q\_149d, q\_149e, q\_149f, q\_149g, q\_149h, ... q\_29a, q\_29b, q\_29c
- No removed in 17 questions: q\_110d, q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, ... q\_136, q\_137, q\_138
- 2 added in *Mother's birth order* (q\_107a), *Father's birth order* (q\_108a), *Father's number of siblings* (q\_108b), *Siblings' birth order* (q\_110a1), *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - Tumor* (q\_65a\_2), *Spinal cord MRI Thoracic - Tumor* (q\_65b\_2) and *Spinal cord MRI Lumbo-sacral - Tumor* (q\_65c\_2)



- 0 added in *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value* (or NF, NA, NR) (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- After added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t), *5th timing* (q\_48e\_t) and *6th timing* (q\_48f\_t)
- cannot convert value **Normal** to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2), *ALSFRS(1) 4. Handwriting* (q\_51\_1.4), *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5) and *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- **Neurologist** added in *First specialist who observed the patient* (q\_148), *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153) and *What specialist 2 observed the patient* (q\_154b\_2)
- factor variable q\_16g, q\_24 and q\_30a doesn't have defined level **No**
- factor variable q\_26, q\_28 and q\_99.c1 doesn't have defined level **Yes**
- cannot convert value **None** to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10), *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116) and *Did specialist 1 made diagnosis* (q\_154d\_1)
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- **other** added in *What cause of death of family member 1* (q\_106\_1b) and *What cause of death of family member 2* (q\_106\_2b)
- **"Unknown"** added in *What other cause of death of family member 1* (q\_106\_1c) and *What other cause of death of family member 2* (q\_106\_2c)
- 6 added in *Mother's number of siblings* (q\_107b) and *Number of siblings* (q\_110a2)
- cannot convert value **Urban area** to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- **Antalya** added in *Medical facility* (facility\_id)
- **Hilmi Uysal** added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucassian**
- **Upper and lower** replaces value **Lower limb** in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level **Distal**
- **5a Left Lower limb - distal** added in *1st region* (q\_48a\_r)
- **5b Left Lower limb - proximal** added in *2nd region* (q\_48b\_r)
- **4a Right Lower limb - distal** added in *3rd region* (q\_48c\_r)
- **4b Right Lower limb - proximal** added in *4th region* (q\_48d\_r)
- **2b Right Upper limb - proximal** added in *5th region* (q\_48e\_r)
- **3b Left Upper limb - proximal** added in *6th region* (q\_48f\_r)
- 2017-11-30 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value **Normal speech processes** to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value **Normal eating habits** to number in *ALSFRS(1) 3.*

- *Swallowing* (q\_51\_1.3)
- cannot convert value **Normal function** to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value **Walks with assistance** to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value **Mild unsteadiness or fatigue** to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- Yes replaces value No in q\_63
- 2014-01-01 replaces value 1905-07-06 in *Date of initiation of Riluzole* (q\_91b)
- Wt/wt (normal) removed in q\_97a
- Pending added in *Abnormal C9orf72 repeat-expansion* (q\_98\_1)
- Father added in *Which family member 1 had died* (q\_106\_1a)
- 62 added in *Age of family member 1 at the moment of death* (q\_106\_1d)
- Son added in *Which family member 2 had died* (q\_106\_2a)
- 65 added in *Age of family member 2 at the moment of death* (q\_106\_2d)
- "housewife" removed in *Main Occupation* (q\_139)
- Cardiologist added in *What specialist 1 observed the patient* (q\_154b\_1)
- Yes added in *Did specialist 2 made diagnosis* (q\_154d\_2)
- "ANTA" removed in *centr\_id*

## Changes to the patient ANTA-0012

- cannot convert value No to number in 64 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 51 questions: *Other type of specialist 7 that observed the patient* (q\_154c\_7), *ALSFRS(2) 1. Speech* (q\_51\_2.1), *ALSFRS(2) 10. Dyspnea* (q\_51\_2.10), *ALSFRS(2) 11. Orthopnea* (q\_51\_2.11), *ALSFRS(2) 12. Respiratory insufficiency* (q\_51\_2.12), *ALSFRS(2) 2. Salivation* (q\_51\_2.2), *ALSFRS(2) 3. Swallowing* (q\_51\_2.3), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 35 questions: *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), *Regular specific diet - Paleo (High-protein, high-fat, low-carbohydrate)* (q\_114h), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 16 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_136, q\_137, q\_138
- cannot convert value Yes to number in 14 questions: q\_149d, q\_149e, q\_149f, q\_149g, q\_149h, q\_152h, q\_156h, ... q\_27c, q\_29a, q\_29c

- 2 added in *Mother's birth order* (q\_107a), *Father's birth order* (q\_108a), *Regular specific diet - No* (q\_114a), *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - NA* (q\_65a\_8), *Spinal cord MRI Thoracic - Tumor* (q\_65b\_2) and *Spinal cord MRI Lumbo-sacral - Tumor* (q\_65c\_2)
- 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- After added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t), *5th timing* (q\_48e\_t), *6th timing* (q\_48f\_t) and *7th timing* (q\_48g\_t)
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), *Did specialist 1 made diagnosis* (q\_154d\_1), *Did specialist 2 made diagnosis* (q\_154d\_2), *Did specialist 3 made diagnosis* (q\_154d\_3) and *Did specialist 4 made diagnosis* (q\_154d\_4)
- Neurologist added in *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153), *What specialist 2 observed the patient* (q\_154b\_2), *What specialist 3 observed the patient* (q\_154b\_3) and *What specialist 4 observed the patient* (q\_154b\_4)
- factor variable q\_26, q\_28, q\_30a and q\_99.c1 doesn't have defined level Yes
- NA removed in *Total Cholesterol lower range* (q\_56b), *LDL Cholesterol lower range* (q\_58b) and *Triglycerides lower range* (q\_59b)
- factor variable q\_16g and q\_24 doesn't have defined level No
- cannot convert value Normal to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2) and *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- No replaces value Yes in q\_63 and q\_94a
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- 4 added in *Mother's number of siblings* (q\_107b) and *Order of specialist 4 that observed the patient* (q\_154a\_4)
- 5 added in *Father's number of siblings* (q\_108b) and *Number of siblings* (q\_110a2)
- 3 added in *Siblings' birth order* (q\_110a1) and *Order of specialist 3 that observed the patient* (q\_154a\_3)
- cannot convert value Urban area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- Internal Medicine added in *First specialist who observed the patient* (q\_148) and *What specialist 1 observed the patient* (q\_154b\_1)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level Caucasian
- Upper and lower replaces value Lower limb in *Limb onset* (q\_18a)

- factor variable *Predominant impairment* (q\_18c) doesn't have defined level Distal
- 4a Right Lower limb - distal added in 1st region (q\_48a\_r)
- 5a Left Lower limb - distal added in 2nd region (q\_48b\_r)
- 2a Right Upper limb - distal added in 3rd region (q\_48c\_r)
- 3a Left Upper limb - distal added in 4th region (q\_48d\_r)
- 1 Oro-facial added in 5th region (q\_48e\_r)
- 8 Thoracic/abdomen added in 6th region (q\_48f\_r)
- 6 Respiratory symptoms added in 7th region (q\_48g\_r)
- 2017-12-19 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value Normal speech processes to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value Normal eating habits to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value Unable to grip pen to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value Normal function to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value Helpless to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value No purposeful leg movement to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value Cannot do to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- cannot convert value Significant difficulty, considering using mechanical respiratory support to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10)
- cannot convert value Unable to sleep to number in *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11)
- cannot convert value Invasive mechanical ventilation by intubation or tracheostomy to number in *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- 2014-01-01 replaces value 1905-07-06 in *Date of initiation of Riluzole* (q\_91b)
- Wt/wt (normal) removed in q\_97a
- Brother added in *Which family member 1 had a history of other severe disease* (q\_105\_1a)
- Cancer prostate added in *What severe disease family member 1 had* (q\_105\_1b)
- Yes removed in q\_111
- "housewife" removed in *Main Occupation* (q\_139)
- "ANTA" removed in centr\_id

## Changes to the patient ANTA-0014

- cannot convert value No to number in 62 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 30 questions: *How many family members 1 had a history of Alzheimer disease* (q\_102a\_2), *Mother's birth order* (q\_107a), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 19 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_145, q\_146, q\_147
- cannot convert value Yes to number in 16 questions: q\_149d, q\_149e, q\_152h, q\_156h, q\_16a, q\_24c, q\_26a, ... q\_28c, q\_29a, q\_29b
- 2 added in *Number of children* (q\_110a), *Siblings' birth order* (q\_110a1), *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - Tumor* (q\_65a\_2), *Spinal cord MRI Thoracic - Tumor* (q\_65b\_2) and *Spinal cord MRI Lumbo-sacral - Tumor* (q\_65c\_2)
- 0 added in *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- After added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t), *5th timing* (q\_48e\_t), *6th timing* (q\_48f\_t) and *7th timing* (q\_48g\_t)
- Neurologist added in *First specialist who observed the patient* (q\_148), *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153), *What specialist 1 observed the patient* (q\_154b\_1) and *What specialist 2 observed the patient* (q\_154b\_2)
- factor variable q\_24, q\_26, q\_28 and q\_99.c1 doesn't have defined level Yes
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), *Did specialist 1 made diagnosis* (q\_154d\_1) and *Did specialist 2 made diagnosis* (q\_154d\_2)
- factor variable q\_16g and q\_30a doesn't have defined level No
- NA removed in *Total Cholesterol lower range* (q\_56b) and *Triglycerides lower range* (q\_59b)

- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- 3 added in *Father's birth order* (q\_108a) and *Number of siblings* (q\_110a2)
- cannot convert value **Urban area** to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- **Antalya** added in *Medical facility* (facility\_id)
- **Hilmi Uysal** added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucassian**
- 2011-04-02 replaces value 2011-02-04 in *Date of Diagnosis* (q\_13)
- **Lower limb** replaces value **Upper limb** in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level **Distal**
- **3a Left Upper limb - distal** added in *1st region* (q\_48a\_r)
- **3b Left Upper limb - proximal** added in *2nd region* (q\_48b\_r)
- **2a Right Upper limb - distal** added in *3rd region* (q\_48c\_r)
- **2b Right Upper limb - proximal** added in *4th region* (q\_48d\_r)
- **5a Left Lower limb - distal** added in *5th region* (q\_48e\_r)
- **4a Right Lower limb - distal** added in *6th region* (q\_48f\_r)
- **1 Oro-facial** added in *7th region* (q\_48g\_r)
- 2017-12-20 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value **Detectable speech disturbances** to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value **Slight but definite excess of saliva in mouth; may have nighttime drooling** to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2)
- cannot convert value **Early eating problems - occasional choking** to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value **Able to grip pen but unable to write** to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value **Needs to be fed** to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value **Needs attendant for self-care** to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value **Can initiate, but not turn or adjust sheets alone** to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value **Nonambulatory functional movement** to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value **Cannot do** to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- cannot convert value **Occurs with >= 1 of the following: eating, bathing, dressing (ADL)** to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10)
- cannot convert value **Some difficulty sleeping at night due to shortness of breath (does not routinely use more than two pillows)** to number in *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11)

- cannot convert value `None` to number in *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- No replaces value `Yes` in q\_63
- 2014-01-01 replaces value 1905-07-06 in *Date of initiation of Riluzole* (q\_91b)
- Wt/wt (`normal`) removed in q\_97a
- Mother added in *Which family member 1 had a history of Alzheimer disease* (q\_102a\_1)
- 5 added in *Mother's number of siblings* (q\_107b)
- 6 added in *Father's number of siblings* (q\_108b)
- "marketing" removed in *Main Occupation* (q\_139)
- "ANTA" removed in `centr_id`

## Changes to the patient ANTA-0019

- cannot convert value `No` to number in 63 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 31 questions: *Mother's birth order* (q\_107a), *Number of children* (q\_110a), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Tumor* (q\_64\_2), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 16 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_136, q\_137, q\_138
- cannot convert value `Yes` to number in 15 questions: q\_149g, q\_156h, q\_16a, q\_24c, q\_25a, q\_25b, q\_25c, ... q\_28a, q\_28b, q\_29a
- 0 added in *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- 2 added in *Siblings' birth order* (q\_110a1), *Number of siblings* (q\_110a2), *Brain MRI - Normal* (q\_64\_1), *Spinal cord MRI Cervical - Normal* (q\_65a\_1), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)
- factor variable q\_24, q\_26, q\_28, q\_30a and q\_99.c1 doesn't have defined level `Yes`

- After added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t), *5th timing* (q\_48e\_t) and *6th timing* (q\_48f\_t)
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116) and *Did specialist 1 made diagnosis* (q\_154d\_1)
- Neurologist added in *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153) and *What specialist 2 observed the patient* (q\_154b\_2)
- Year of initiation of smoking (q\_88b) and Year of interruption of smoking (q\_88d) doesn't allow for tagged NA 2
- 5 added in *Mother's number of siblings* (q\_107b) and *Father's number of siblings* (q\_108b)
- "trainer" removed in *Main Occupation* (q\_139) and *Second Occupation* (q\_141)
- cannot convert value Urban area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- General Practitioner added in *First specialist who observed the patient* (q\_148) and *What specialist 1 observed the patient* (q\_154b\_1)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- factor variable Ethnicity (q\_7) doesn't have defined level Caucassian
- 2016-08-15 replaces value 2015-08-15 in *Date of Invasive ventilation* (q\_14)
- factor variable q\_16g doesn't have defined level No
- Upper and lower replaces value Lower limb in *Limb onset* (q\_18a)
- factor variable Predominant impairment (q\_18c) doesn't have defined level Distal
- 5a Left Lower limb - distal added in *1st region* (q\_48a\_r)
- 4a Right Lower limb - distal added in *2nd region* (q\_48b\_r)
- 3a Left Upper limb - distal added in *3rd region* (q\_48c\_r)
- 2a Right Upper limb - distal added in *4th region* (q\_48d\_r)
- 6 Respiratory symptoms added in *5th region* (q\_48e\_r)
- 7 Neck added in *6th region* (q\_48f\_r)
- 2018-02-08 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value Loss of useful speech to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value Marked drooling; requires constant tissue or handkerchief to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2)
- cannot convert value NPO (exclus. parenteral or enteral feeding) to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value Able to grip pen but unable to write to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value Food must be cut by someone, but can still feed slowly to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value Total dependence to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)



- cannot convert value **Helpless** to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value **No purposeful leg movement** to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value **Cannot do** to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- cannot convert value **Significant difficulty, considering using mechanical respiratory support** to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10)
- cannot convert value **Some difficulty sleeping at night due to shortness of breath (does not routinely use more than two pillows)** to number in *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11)
- cannot convert value **Invasive mechanical ventilation by intubation or tracheostomy** to number in *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- No replaces value **Yes** in q\_63
- 2014-01-01 replaces value 1905-07-06 in *Date of initiation of Riluzole* (q\_91b)
- Wt/wt (normal) removed in q\_97a
- 3 added in *Father's birth order* (q\_108a)
- Yes removed in q\_111
- Yes added in *Did specialist 2 made diagnosis* (q\_154d\_2)
- "ANTA" removed in *centr\_id*

## Changes to the patient ANTA-0020

- cannot convert value **No** to number in 67 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 29 questions: *Father's birth order* (q\_108a), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), *Brain MRI - Hypoxia* (q\_64\_6), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 16 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_136, q\_137, q\_138
- cannot convert value **Yes** to number in 11 questions: q\_152d, q\_152e, q\_152h, q\_156h, q\_16a, q\_24c, q\_25a, ... q\_26b, q\_27a, q\_28b

- 2 added in *Mother's birth order* (q\_107a), *Siblings' birth order* (q\_110a1), *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - Tumor* (q\_65a\_2), *Spinal cord MRI Thoracic - Tumor* (q\_65b\_2) and *Spinal cord MRI Lumbo-sacral - Tumor* (q\_65c\_2)
- 0 added in *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- factor variable q\_24, q\_26, q\_28, q\_30a and q\_99.c1 doesn't have defined level Yes
- After added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t), *6th timing* (q\_48f\_t) and *7th timing* (q\_48g\_t)
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), *Did specialist 1 made diagnosis* (q\_154d\_1) and *Did specialist 2 made diagnosis* (q\_154d\_2)
- cannot convert value None to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10), *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- Neurologist added in *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153) and *What specialist 2 observed the patient* (q\_154b\_2)
- Same time added in *5th timing* (q\_48e\_t) and *8th timing* (q\_48h\_t)
- Year of initiation of smoking (q\_88b) and Year of interruption of smoking (q\_88d) doesn't allow for tagged NA 2
- 3 added in *Mother's number of siblings* (q\_107b) and *Number of siblings* (q\_110a2)
- cannot convert value Urban area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- General Practitioner added in *First specialist who observed the patient* (q\_148) and *What specialist 1 observed the patient* (q\_154b\_1)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- factor variable Ethnicity (q\_7) doesn't have defined level Caucassian
- factor variable q\_16g doesn't have defined level No
- Lower limb replaces value Upper limb in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level Distal
- Positive added in q\_43
- 2a Right Upper limb - distal added in *1st region* (q\_48a\_r)
- 3a Left Upper limb - distal added in *2nd region* (q\_48b\_r)
- 2b Right Upper limb - proximal added in *3rd region* (q\_48c\_r)
- 3b Left Upper limb - proximal added in *4th region* (q\_48d\_r)
- 1 Oro-facial added in *5th region* (q\_48e\_r)
- 5a Left Lower limb - distal added in *6th region* (q\_48f\_r)
- 4a Right Lower limb - distal added in *7th region* (q\_48g\_r)

- 8 Thoracic/abdomen added in *8th region* (q\_48h\_r)
- Lumbo-sacral replaces value Thoracic in *Region3* (q\_50a)
- cannot convert value Speech combined with nonvocal communication to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value Slight but definite excess of saliva in mouth; may have nighttime drooling to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2)
- cannot convert value Dietary consistency changes to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value Unable to grip pen to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value Needs to be fed to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value Total dependence to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value Can turn alone or adjust sheets, but with great difficulty to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value Early ambulation difficulties to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value Needs assistance to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- No replaces value Yes in q\_63
- 2014-01-01 replaces value 1905-07-06 in *Date of initiation of Riluzole* (q\_91b)
- Wt/wt (normal) removed in q\_97a
- 9 added in *Father's number of siblings* (q\_108b)
- Yes added in q\_111
- "farmer" removed in *Main Occupation* (q\_139)
- "ANTA" removed in *centr\_id*

## Changes to the patient ANTA-0023

- cannot convert value No to number in 67 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 30 questions: *Mother's birth order* (q\_107a), *Siblings' birth order* (q\_110a1), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI -*

- Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 16 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_136, q\_137, q\_138
  - cannot convert value **Yes** to number in 11 questions: q\_152d, q\_152e, q\_152h, q\_156h, q\_16a, q\_26a, q\_26b, ... q\_28a, q\_28b, q\_29a
  - 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
  - 2 added in *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - Tumor* (q\_65a\_2), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)
  - **Neurologist** added in *First specialist who observed the patient* (q\_148), *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153), *What specialist 1 observed the patient* (q\_154b\_1) and *What specialist 2 observed the patient* (q\_154b\_2)
  - **After** added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t) and *5th timing* (q\_48e\_t)
  - No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), *Did specialist 1 made diagnosis* (q\_154d\_1) and *Did specialist 2 made diagnosis* (q\_154d\_2)
  - factor variable q\_26, q\_30a and q\_99.c1 doesn't have defined level **Yes**
  - factor variable q\_16g and q\_24 doesn't have defined level **No**
  - *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
  - 4 added in *Father's birth order* (q\_108a) and *Number of siblings* (q\_110a2)
  - cannot convert value **Rural area** to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
  - **Antalya** added in *Medical facility* (facility\_id)
  - **Hilmi Uysal** added in *Physician recording the data* (person\_id)
  - factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucassian**
  - **Upper limb** replaces value **Upper and lower** in *Limb onset* (q\_18a)
  - factor variable *Predominant impairment* (q\_18c) doesn't have defined level **Distal**
  - 2 **Right Upper limb - distal and proximal** added in *1st region* (q\_48a\_r)
  - 3 **Left Upper limb - distal and proximal** added in *2nd region* (q\_48b\_r)
  - 4 **Right Lower limb - distal and proximal** added in *3rd region* (q\_48c\_r)
  - 5 **Left Lower limb - distal and proximal** added in *4th region* (q\_48d\_r)

- 7 Neck added in *5th region* (q\_48e\_r)
- Bulbar replaces value Thoracic in *Region3* (q\_50a)
- 2016-09-28 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value Normal speech processes to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value Normal to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2)
- cannot convert value Normal eating habits to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value Able to grip pen but unable to write to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value Food must be cut by someone, but can still feed slowly to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value Needs attendant for self-care to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value Can initiate, but not turn or adjust sheets alone to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value Nonambulatory functional movement to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value Cannot do to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- cannot convert value Occurs with >= 1 of the following: eating, bathing, dressing (ADL) to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10)
- cannot convert value Some difficulty sleeping at night due to shortness of breath (does not routinely use more than two pillows) to number in *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11)
- cannot convert value None to number in *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- No replaces value Yes in q\_63
- Yes replaces value No in q\_89a
- "Lithium" added in *Drug(s) used in psychiatric medication* (q\_89b)
- 2014-01-01 replaces value 1905-07-06 in *Date of initiation of Riluzole* (q\_91b)
- "Homozygous D90A" replaces value "Homozigot D90A" in *SOD1 mutation type* (q\_97b)
- 6 added in *Mother's number of siblings* (q\_107b)
- 5 added in *Father's number of siblings* (q\_108b)
- 3 added in *Number of children* (q\_110a)
- Yes added in q\_111
- "housewife" removed in *Main Occupation* (q\_139)
- "ANTA" removed in *centr\_id*

## Changes to the patient ANTA-0025

- cannot convert value No to number in 62 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 33 questions: *How many family members 1 had a history of Alzheimer disease* (q\_102a\_2), *Father's birth order* (q\_108a), *Father's number of siblings* (q\_108b), *Siblings' birth order* (q\_110a1), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), ... *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8), *Mean number of packs/day* (q\_88e)
- cannot convert value Yes to number in 16 questions: q\_149d, q\_149e, q\_149f, q\_149g, q\_149h, q\_156h, q\_16a, ... q\_28a, q\_28b, q\_28c
- No removed in 13 questions: q\_123, q\_125, q\_126, q\_127, q\_129, q\_130, q\_131, ... q\_135, q\_136, q\_137
- factor variable q\_124, q\_128, q\_138, q\_24, q\_26, q\_28, q\_30a and q\_99.c1 doesn't have defined level Yes
- 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b) and *ALS depression inventory lower range* (q\_47c)
- 2 added in *Number of children* (q\_110a), *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - Tumor* (q\_65a\_2), *Spinal cord MRI Thoracic - Tumor* (q\_65b\_2) and *Spinal cord MRI Lumbo-sacral - Tumor* (q\_65c\_2)
- After added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t), *5th timing* (q\_48e\_t) and *6th timing* (q\_48f\_t)
- Neurologist added in *First specialist who observed the patient* (q\_148), *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153), *What specialist 1 observed the patient* (q\_154b\_1) and *What specialist 2 observed the patient* (q\_154b\_2)
- 3 added in *Mother's birth order* (q\_107a) and *Number of siblings* (q\_110a2)
- No added in *Head/Neck trauma in the last 5 years* (q\_115) and *Did specialist 1 made diagnosis* (q\_154d\_1)
- cannot convert value Urban area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Yusal added in *Physician recording the data* (person\_id)

- factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucassian**
- 2016-09-21 replaces value 2016-09-10 in *Date of Invasive ventilation* (q\_14)
- factor variable q\_16g doesn't have defined level **No**
- **Lower limb** replaces value **Upper limb** in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level **Distal**
- **3a Left Upper limb - distal** added in *1st region* (q\_48a\_r)
- **5a Left Lower limb - distal** added in *2nd region* (q\_48b\_r)
- **2a Right Upper limb - distal** added in *3rd region* (q\_48c\_r)
- **4a Right Lower limb - distal** added in *4th region* (q\_48d\_r)
- **1 Oro-facial** added in *5th region* (q\_48e\_r)
- **6 Respiratory symptoms** added in *6th region* (q\_48f\_r)
- 2016-09-20 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value **Intelligible with repeating** to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value **Marked excess of saliva with some drooling** to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2)
- cannot convert value **Dietary consistency changes** to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value **Unable to grip pen** to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value **Needs to be fed** to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value **Total dependence** to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value **Helpless** to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value **No purposeful leg movement** to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value **Cannot do** to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- cannot convert value **Significant difficulty, considering using mechanical respiratory support** to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10)
- cannot convert value **Some difficulty sleeping at night due to shortness of breath (does not routinely use more than two pillows)** to number in *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11)
- cannot convert value **Invasive mechanical ventilation by intubation or tracheostomy** to number in *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- **NA** replaces value **8** in *ALSFRS-R total* (q\_51\_1.score)
- **NA** replaces value **NA** in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- **No** replaces value **Yes** in q\_63
- **1985** replaces value **NA** in *Year of initiation of smoking* (q\_88b)
- **2010** replaces value **NA** in *Year of interruption of smoking* (q\_88d)

- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- Wt/wt (normal) removed in q\_97a
- Mother added in *Which family member 1 had a history of Alzheimer disease* (q\_102a\_1)
- 4 added in *Mother's number of siblings* (q\_107b)
- Head added in *Head/Neck trauma > 5 years* (q\_116)
- "Driver" removed in *Main Occupation* (q\_139)
- "EMG" removed in *Investigation requested by the 1st specialist* (q\_149)
- Yes added in *Did specialist 2 made diagnosis* (q\_154d\_2)
- "ANTA" removed in `centr_id`

## Changes to the patient ANTA-0026

- cannot convert value No to number in 71 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 30 questions: *Father's birth order* (q\_108a), *Siblings' birth order* (q\_110a1), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Tumor* (q\_64\_2), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 17 questions: q\_111, q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, ... q\_136, q\_137, q\_138
- cannot convert value Yes to number in q\_149b, q\_149e, q\_152h, q\_156h, q\_16a, q\_26a and q\_28a
- 0 added in *Age of family member 1 at the moment of death* (q\_106\_1d), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- After added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t), *5th timing* (q\_48e\_t) and *6th timing* (q\_48f\_t)
- 2 added in *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Normal* (q\_64\_1), *Spinal cord MRI Cervical - Normal* (q\_65a\_1), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)
- cannot convert value Normal to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2), *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7), *ALSFRS(1) 8. Walking* (q\_51\_1.8) and *ALSFRS(1) 9. Climb-*



ing Stairs (q\_51\_1.9)

- factor variable q\_16g, q\_24 and q\_30a doesn't have defined level No
- factor variable q\_26, q\_28 and q\_99.c1 doesn't have defined level Yes
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116) and *Did specialist 1 made diagnosis* (q\_154d\_1)
- Neurologist added in *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153) and *What specialist 2 observed the patient* (q\_154b\_2)
- cannot convert value None to number in *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- Year of initiation of smoking (q\_88b) and Year of interruption of smoking (q\_88d) doesn't allow for tagged NA 2
- cannot convert value Urban area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- General Practitioner added in *First specialist who observed the patient* (q\_148) and *What specialist 1 observed the patient* (q\_154b\_1)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- factor variable Ethnicity (q\_7) doesn't have defined level Caucasian
- Upper and lower replaces value Lower limb in *Limb onset* (q\_18a)
- Distal and proximal replaces value Proximal in *Predominant impairment* (q\_18c)
- 3b Left Upper limb - proximal added in *1st region* (q\_48a\_r)
- 5b Left Lower limb - proximal added in *2nd region* (q\_48b\_r)
- 3a Left Upper limb - distal added in *3rd region* (q\_48c\_r)
- 5a Left Lower limb - distal added in *4th region* (q\_48d\_r)
- 2a Right Upper limb - distal added in *5th region* (q\_48e\_r)
- 2b Right Upper limb - proximal added in *6th region* (q\_48f\_r)
- Cervical replaces value Lumbo-sacral in *Region1* (q\_49a)
- Lumbo-sacral replaces value Cervical in *Region2* (q\_49b)
- 2016-03-04 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value Normal speech processes to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value Normal eating habits to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value Slow or sloppy; all words are legible to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value Somewhat slow and clumsy, but no help needed to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value Independent and complete self-care with effort of decreased efficiency to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value Occurs with >= 1 of the following: eating, bathing, dressing (ADL) to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10)

- NA replaces value NA in *ALSFERS(1) Rate of decay* (q\_51\_1.rate)
- No replaces value Yes in q\_63
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- Mutation found removed in q\_97a
- "SNP" removed in *SOD1 mutation type* (q\_97b)
- Son added in *Which family member 1 had died* (q\_106\_1a)
- Other violent death added in *What cause of death of family member 1* (q\_106\_1b)
- 6 added in *Mother's birth order* (q\_107a)
- 7 added in *Mother's number of siblings* (q\_107b)
- 4 added in *Father's number of siblings* (q\_108b)
- 3 added in *Number of siblings* (q\_110a2)
- "housewife" removed in *Main Occupation* (q\_139)
- Yes added in *Did specialist 2 made diagnosis* (q\_154d\_2)
- "ANTA" removed in centr\_id

## Changes to the patient ANTA-0054

- cannot convert value No to number in 61 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 29 questions: *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Tumor* (q\_64\_2), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), *Brain MRI - Hypoxia* (q\_64\_6), *Brain MRI - NA* (q\_64\_7), ... *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8), *Mean number of packs/day* (q\_88e)
- cannot convert value Yes to number in 17 questions: q\_119c, q\_152d, q\_156h, q\_16a, q\_24b, q\_24c, q\_25a, ... q\_29a, q\_29b, q\_29c
- No removed in 16 questions: q\_110d, q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, ... q\_135, q\_136, q\_138
- 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b) and *ALS depression inventory lower range* (q\_47c)
- 2 added in *Siblings' birth order* (q\_110a1), *Number of siblings* (q\_110a2), *Brain MRI - Normal* (q\_64\_1), *Spinal cord MRI Cervical - Normal* (q\_65a\_1), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)

- factor variable `q_16g`, `q_24`, `q_26` and `q_30a` doesn't have defined level `No`
- "Cleaner" removed in *Main Occupation* (`q_139`), *Main Occupation* (`q_140`), *Second Occupation* (`q_141`) and *Second Occupation* (`q_142`)
- factor variable `q_137`, `q_28` and `q_99.c1` doesn't have defined level `Yes`
- 4 added in *Mother's birth order* (`q_107a`) and *Mother's number of siblings* (`q_107b`)
- 3 added in *Father's birth order* (`q_108a`) and *Father's number of siblings* (`q_108b`)
- No added in *Head/Neck trauma in the last 5 years* (`q_115`) and *Head/Neck trauma > 5 years* (`q_116`)
- cannot convert value `Urban area` to number in *Lives in Rural Area/Urban* (`q_143a`) and *Lives in Rural Area/Urban* (`q_144a`)
- Orthopaedist added in *First specialist who observed the patient* (`q_148`) and *What specialist 1 observed the patient* (`q_154b_1`)
- Antalya added in *Medical facility* (`facility_id`)
- Hilmi Uysal added in *Physician recording the data* (`person_id`)
- factor variable *Ethnicity* (`q_7`) doesn't have defined level `Caucassian`
- `Upper and lower` replaces value `Lower limb` in *Limb onset* (`q_18a`)
- factor variable *Predominant impairment* (`q_18c`) doesn't have defined level `Distal`
- No replaces value `Yes` in `q_37`
- Lumbo-sacral removed in *Region1* (`q_49a`)
- Cervical removed in *Region2* (`q_49b`)
- Bulbar removed in *Region3* (`q_50a`)
- 2017-06-24 added in *ALSFRS(1) Acquisition date* (`q_51_1.date`)
- cannot convert value `Intelligible with repeating` to number in *ALSFRS(1) 1. Speech* (`q_51_1.1`)
- cannot convert value `Slight but definite excess of saliva in mouth; may have nighttime drooling` to number in *ALSFRS(1) 2. Salivation* (`q_51_1.2`)
- cannot convert value `Early eating problems - occasional choking` to number in *ALSFRS(1) 3. Swallowing* (`q_51_1.3`)
- cannot convert value `Slow or sloppy; all words are legible` to number in *ALSFRS(1) 4. Handwriting* (`q_51_1.4`)
- cannot convert value `Can cut most foods, although clumsy and slow; some help needed` to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (`q_51_1.5`)
- cannot convert value `Intermittent assistance or substitute methods` to number in *ALSFRS(1) 6. Dressing and Hygiene* (`q_51_1.6`)
- cannot convert value `Normal` to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (`q_51_1.7`)
- cannot convert value `Early ambulation difficulties` to number in *ALSFRS(1) 8. Walking* (`q_51_1.8`)
- cannot convert value `Slow` to number in *ALSFRS(1) 9. Climbing Stairs* (`q_51_1.9`)
- cannot convert value `Occurs when walking` to number in *ALSFRS(1) 10.*

*Dyspnea* (q\_51\_1.10)

- cannot convert value **Unable to sleep** to number in *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11)
- cannot convert value **Invasive mechanical ventilation by intubation or tracheostomy** to number in *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- 28 removed in *ALSFRS-R total* (q\_51\_1.score)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- *Year of initiation of smoking* (q\_88b) doesn't allow for tagged NA 2
- **Wt/wt (normal)** removed in q\_97a
- **Father** added in *Which family member 1 had died* (q\_106\_1a)
- **other** added in *What cause of death of family member 1* (q\_106\_1b)
- **"unknown"** added in *What other cause of death of family member 1* (q\_106\_1c)
- 84 added in *Age of family member 1 at the moment of death* (q\_106\_1d)
- **Neurosurgeon** added in *Second specialist who observed the patient* (q\_150)
- **Neurologist** added in *Specialist who made the diagnosis* (q\_153)
- **Yes** added in *Did specialist 1 made diagnosis* (q\_154d\_1)
- **"ANTA"** removed in **centr\_id**
- 29 replaces value 54 in **x**

## Changes to the patient ANTA-0055

- cannot convert value **No** to number in 65 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 30 questions: *Father's birth order* (q\_108a), *Father's number of siblings* (q\_108b), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 16 questions: q\_110d, q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, ... q\_135, q\_136, q\_137
- cannot convert value **Yes** to number in 13 questions: q\_152g, q\_156h, q\_16b, q\_24b, q\_24c, q\_25a, q\_26a, ... q\_28b, q\_28c, q\_29a
- 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range*

- (q\_47c) and *Mean number of packs/day* (q\_88e)
- factor variable q\_138, q\_24, q\_26 and q\_99.c1 doesn't have defined level Yes
- 2 added in *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - Normal* (q\_65a\_1), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)
- "Housewife" removed in *Main Occupation* (q\_139), *Main Occupation* (q\_140), *Second Occupation* (q\_141) and *Second Occupation* (q\_142)
- factor variable q\_16g, q\_28 and q\_30a doesn't have defined level No
- cannot convert value None to number in *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- 4 added in *Mother's birth order* (q\_107a) and *Mother's number of siblings* (q\_107b)
- No added in *Head/Neck trauma in the last 5 years* (q\_115) and *Head/Neck trauma > 5 years* (q\_116)
- cannot convert value Urban area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- Pneumologist added in *First specialist who observed the patient* (q\_148) and *What specialist 1 observed the patient* (q\_154b\_1)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level Caucassian
- 2017-07-26 removed in *Date of Death* (q\_15)
- Lower limb replaces value Upper limb in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level Distal
- Bulbar removed in *Region1* (q\_49a)
- Cervical removed in *Region2* (q\_49b)
- factor variable *Region3* (q\_50a) doesn't have defined level Cervical
- 2017-06-24 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value Speech combined with nonvocal communication to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value Moderately excessive saliva; may have minimal drooling to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2)
- cannot convert value Dietary consistency changes to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value Not all words are legible to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value Food must be cut by someone, but can still feed slowly to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value Needs attendant for self-care to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value Can initiate, but not turn or adjust sheets

- alone to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value **Nonambulatory functional movement** to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value **Mild unsteadiness or fatigue** to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- cannot convert value **Occurs at rest Shortness of breath at rest, difficulty breathing when either sitting or lying** to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- Yes replaces value No in q\_63
- Wt/wt (normal) removed in q\_97a
- Father added in *Which family member 1 had died* (q\_106\_1a)
- other added in *What cause of death of family member 1* (q\_106\_1b)
- "UNKNOWN" added in *What other cause of death of family member 1* (q\_106\_1c)
- 50 added in *Age of family member 1 at the moment of death* (q\_106\_1d)
- 13 added in *Number of children* (q\_110a)
- 3 added in *Siblings' birth order* (q\_110a1)
- 8 added in *Number of siblings* (q\_110a2)
- Other added in *Second specialist who observed the patient* (q\_150)
- Neurologist added in *Specialist who made the diagnosis* (q\_153)
- Yes added in *Did specialist 1 made diagnosis* (q\_154d\_1)
- "ANTA" removed in *centr\_id*
- 30 replaces value 55 in *x*

## Changes to the patient ANTA-0007

- cannot convert value No to number in 67 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 29 questions: *Mother's birth order* (q\_107a), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), *Brain MRI - Hypoxia* (q\_64\_6), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 19 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_145, q\_146, q\_147

- cannot convert value **Yes** to number in 11 questions: q\_149d, q\_149e, q\_149f, q\_149g, q\_152h, q\_156h, q\_16a, ... q\_27a, q\_27b, q\_28a
- 0 added in *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- 2 added in *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - Tumor* (q\_65a\_2), *Spinal cord MRI Thoracic - Tumor* (q\_65b\_2) and *Spinal cord MRI Lumbo-sacral - Tumor* (q\_65c\_2)
- **Neurologist** added in *First specialist who observed the patient* (q\_148), *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153), *What specialist 1 observed the patient* (q\_154b\_1) and *What specialist 2 observed the patient* (q\_154b\_2)
- **After** added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t) and *5th timing* (q\_48e\_t)
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), *Did specialist 1 made diagnosis* (q\_154d\_1) and *Did specialist 2 made diagnosis* (q\_154d\_2)
- factor variable q\_16g, q\_24 and q\_30a doesn't have defined level **No**
- factor variable q\_26, q\_28 and q\_99.c1 doesn't have defined level **Yes**
- cannot convert value **Normal** to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2), *ALSFRS(1) 8. Walking* (q\_51\_1.8) and *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- cannot convert value **None** to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10), *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged **NA 2**
- 3 added in *Mother's number of siblings* (q\_107b) and *Father's birth order* (q\_108a)
- cannot convert value **Urban area** to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- **Antalya** added in *Medical facility* (facility\_id)
- **Hilmi Uysal** added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucassian**
- 2014-05-04 replaces value 2014-05-02 in *Date of Diagnosis* (q\_13)
- **Lower limb** replaces value **Upper limb** in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level **Distal**
- **2a Right Upper limb - distal** added in *1st region* (q\_48a\_r)
- **3a Left Upper limb - distal** added in *2nd region* (q\_48b\_r)
- **2b Right Upper limb - proximal** added in *3rd region* (q\_48c\_r)
- **3b Left Upper limb - proximal** added in *4th region* (q\_48d\_r)
- **4a Right Lower limb - distal** added in *5th region* (q\_48e\_r)
- 2017-11-30 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)

- cannot convert value `Normal speech processes` to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value `Normal eating habits` to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value `Unable to grip pen` to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value `Food must be cut by someone, but can still feed slowly` to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value `Intermittent assistance or substitute methods` to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value `Somewhat slow and clumsy, but no help needed` to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- No replaces value Yes in q\_63
- Yes replaces value No in q\_91a
- 2014-01-01 replaces value 1905-07-06 in *Date of initiation of Riluzole* (q\_91b)
- Wt/wt (normal) removed in q\_97a
- 7 added in *Father's number of siblings* (q\_108b)
- 4 added in *Siblings' birth order* (q\_110a1)
- 9 added in *Number of siblings* (q\_110a2)
- "warden" removed in *Main Occupation* (q\_139)
- "ANTA" removed in `centr_id`

## Changes to the patient ANTA-0009

- cannot convert value No to number in 65 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 29 questions: *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), *Brain MRI - Hypoxia* (q\_64\_6), *Brain MRI - NA* (q\_64\_7), ... *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8), *Mean number of packs/day* (q\_88e)
- No removed in 16 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_136, q\_137, q\_138



- cannot convert value **Yes** to number in 13 questions: q\_149d, q\_149e, q\_149g, q\_156h, q\_16a, q\_24c, q\_26a, ... q\_28a, q\_28b, q\_29b
- factor variable q\_24, q\_26, q\_28, q\_30a and q\_99.c1 doesn't have defined level **Yes**
- 0 added in *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b) and *ALS depression inventory lower range* (q\_47c)
- 2 added in *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - Tumor* (q\_65a\_2), *Spinal cord MRI Thoracic - Tumor* (q\_65b\_2) and *Spinal cord MRI Lumbosacral - Tumor* (q\_65c\_2)
- **Neurologist** added in *First specialist who observed the patient* (q\_148), *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153) and *What specialist 2 observed the patient* (q\_154b\_2)
- **After** added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t) and *4th timing* (q\_48d\_t)
- cannot convert value **Normal** to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2), *ALSFRS(1) 8. Walking* (q\_51\_1.8) and *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- cannot convert value **None** to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10), *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- 4 added in *Father's birth order* (q\_108a), *Father's number of siblings* (q\_108b) and *Siblings' birth order* (q\_110a1)
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116) and *Did specialist 1 made diagnosis* (q\_154d\_1)
- cannot convert value **Somewhat slow and clumsy, but no help needed** to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5) and *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- cannot convert value **Rural area** to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- **Antalya** added in *Medical facility* (facility\_id)
- **Hilmi Uysal** added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucassian**
- factor variable q\_16g doesn't have defined level **No**
- **Lower limb** replaces value **Upper limb** in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level **Distal**
- **2b Right Upper limb - proximal** added in *1st region* (q\_48a\_r)
- **2a Right Upper limb - distal** added in *2nd region* (q\_48b\_r)
- **3b Left Upper limb - proximal** added in *3rd region* (q\_48c\_r)
- **3a Left Upper limb - distal** added in *4th region* (q\_48d\_r)

- Bulbar removed in *Region2* (q\_49b)
- 2017-12-04 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value **Normal speech processes** to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value **Normal eating habits** to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value **Slow or sloppy; all words are legible** to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value **Independent and complete self-care with effort of decreased efficiency** to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- No replaces value Yes in q\_63
- 2014-01-01 replaces value 1905-07-06 in *Date of initiation of Riluzole* (q\_91b)
- Wt/wt (normal) removed in q\_97a
- 3 added in *Mother's birth order* (q\_107a)
- 5 added in *Mother's number of siblings* (q\_107b)
- 6 added in *Number of siblings* (q\_110a2)
- "driver" removed in *Main Occupation* (q\_139)
- "farmer" removed in *Second Occupation* (q\_141)
- Cardiologist added in *What specialist 1 observed the patient* (q\_154b\_1)
- Yes added in *Did specialist 2 made diagnosis* (q\_154d\_2)
- "ANTA" removed in *centr\_id*

## Changes to the patient ANTA-0010

- cannot convert value No to number in 69 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 30 questions: *Mother's birth order* (q\_107a), *Father's birth order* (q\_108a), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 16 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_136, q\_137, q\_138
- cannot convert value Yes to number in q\_156h, q\_16a, q\_26a, q\_26b, q\_26c, q\_27a, q\_27b, q\_28a and q\_28b

- 0 added in *Cognition - ECAS lower range* (q\_45b), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- After added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t), *4th timing* (q\_48d\_t), *5th timing* (q\_48e\_t) and *6th timing* (q\_48f\_t)
- 2 added in *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - Normal* (q\_65a\_1), *Spinal cord MRI Thoracic - Tumor* (q\_65b\_2) and *Spinal cord MRI Lumbo-sacral - Tumor* (q\_65c\_2)
- factor variable q\_26, q\_28, q\_30a and q\_99.c1 doesn't have defined level Yes
- cannot convert value Normal to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2), *ALSFRS(1) 4. Handwriting* (q\_51\_1.4), *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5) and *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), *Did specialist 1 made diagnosis* (q\_154d\_1) and *Did specialist 2 made diagnosis* (q\_154d\_2)
- Neurologist added in *First specialist who observed the patient* (q\_148), *Second specialist who observed the patient* (q\_150), *What specialist 1 observed the patient* (q\_154b\_1) and *What specialist 2 observed the patient* (q\_154b\_2)
- cannot convert value None to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10), *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- factor variable q\_16g and q\_24 doesn't have defined level No
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- 3 added in *Mother's number of siblings* (q\_107b) and *Number of children* (q\_110a)
- cannot convert value Urban area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level Caucassian
- Upper and lower added in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level Distal
- 0 replaces value 136 in *Cognition - ECAS upper range* (q\_45c)
- 5a Left Lower limb - distal added in *1st region* (q\_48a\_r)
- 4a Right Lower limb - distal added in *2nd region* (q\_48b\_r)
- 5b Left Lower limb - proximal added in *3rd region* (q\_48c\_r)
- 4b Right Lower limb - proximal added in *4th region* (q\_48d\_r)
- 3b Left Upper limb - proximal added in *5th region* (q\_48e\_r)
- 2b Right Upper limb - proximal added in *6th region* (q\_48f\_r)

- Thoracic removed in *Region3* (q\_50a)
- 2017-12-04 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value Normal speech processes to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value Normal eating habits to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value Normal function to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value Early ambulation difficulties to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value Needs assistance to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- No replaces value Yes in q\_63
- 2014-01-01 replaces value 1905-07-06 in *Date of initiation of Riluzole* (q\_91b)
- Wt/wt (normal) removed in q\_97a
- 5 added in *Father's number of siblings* (q\_108b)
- 6 added in *Siblings' birth order* (q\_110a1)
- 7 added in *Number of siblings* (q\_110a2)
- "repairman" removed in *Main Occupation* (q\_139)
- "ANTA" removed in centr\_id

## Changes to the patient ANTA-0013

- cannot convert value No to number in 66 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 29 questions: *Siblings' birth order* (q\_110a1), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), *Brain MRI - Hypoxia* (q\_64\_6), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 18 questions: q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, q\_130, ... q\_145, q\_146, q\_147
- cannot convert value Yes to number in 12 questions: q\_149d, q\_149e, q\_149f, q\_152h, q\_156h, q\_16a, q\_26b, ... q\_27c, q\_28a, q\_28b
- 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition -*

- ECAS lower range (q\_45b), Cognition - ECAS upper range (q\_45c), ALS depression inventory value (or NF, NA, NR) (q\_47a), ALS depression inventory upper range (q\_47b), ALS depression inventory lower range (q\_47c) and Mean number of packs/day (q\_88e)*
- 2 added in *Mother's birth order (q\_107a), Order of specialist 2 that observed the patient (q\_154a\_2), Brain MRI - Tumor (q\_64\_2), Spinal cord MRI Cervical - Tumor (q\_65a\_2), Spinal cord MRI Thoracic - Normal (q\_65b\_1) and Spinal cord MRI Lumbo-sacral - Normal (q\_65c\_1)*
  - cannot convert value **Normal** to number in *ALSFRS(1) 2. Salivation (q\_51\_1.2), ALSFRS(1) 4. Handwriting (q\_51\_1.4), ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes (q\_51\_1.7), ALSFRS(1) 8. Walking (q\_51\_1.8) and ALSFRS(1) 9. Climbing Stairs (q\_51\_1.9)*
  - **Neurologist** added in *First specialist who observed the patient (q\_148), Second specialist who observed the patient (q\_150), Specialist who made the diagnosis (q\_153), What specialist 1 observed the patient (q\_154b\_1) and What specialist 2 observed the patient (q\_154b\_2)*
  - factor variable **q\_123, q\_26, q\_28 and q\_99.c1** doesn't have defined level **Yes**
  - No added in *Head/Neck trauma in the last 5 years (q\_115), Head/Neck trauma > 5 years (q\_116), Did specialist 1 made diagnosis (q\_154d\_1) and Did specialist 2 made diagnosis (q\_154d\_2)*
  - factor variable **q\_16g, q\_24 and q\_30a** doesn't have defined level **No**
  - cannot convert value **None** to number in *ALSFRS(1) 10. Dyspnea (q\_51\_1.10), ALSFRS(1) 11. Orthopnea (q\_51\_1.11) and ALSFRS(1) 12. Respiratory insufficiency (q\_51\_1.12)*
  - *Year of initiation of smoking (q\_88b) and Year of interruption of smoking (q\_88d)* doesn't allow for tagged **NA 2**
  - cannot convert value **Urban area** to number in *Lives in Rural Area/Urban (q\_143a) and Lives in Rural Area/Urban (q\_144a)*
  - **Antalya** added in *Medical facility (facility\_id)*
  - **Hilmi Uysal** added in *Physician recording the data (person\_id)*
  - factor variable **Ethnicity (q\_7)** doesn't have defined level **Caucassian**
  - **Lower limb** replaces value **Upper limb** in *Limb onset (q\_18a)*
  - **Distal and proximal** replaces value **Proximal** in *Predominant impairment (q\_18c)*
  - **2b Right Upper limb - proximal** added in *1st region (q\_48a\_r)*
  - **3b Left Upper limb - proximal** added in *2nd region (q\_48b\_r)*
  - **After** added in *2nd timing (q\_48b\_t)*
  - **2017-12-20** added in *ALSFRS(1) Acquisition date (q\_51\_1.date)*
  - cannot convert value **Normal speech processes** to number in *ALSFRS(1) 1. Speech (q\_51\_1.1)*
  - cannot convert value **Normal eating habits** to number in *ALSFRS(1) 3. Swallowing (q\_51\_1.3)*
  - cannot convert value **Somewhat slow and clumsy, but no help needed** to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils (q\_51\_1.5)*

- cannot convert value Independent and complete self-care with effort of decreased efficiency to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- No replaces value Yes in q\_63
- Yes replaces value No in q\_91a
- 2014-01-01 replaces value 1905-07-06 in *Date of initiation of Riluzole* (q\_91b)
- Wt/wt (normal) removed in q\_97a
- 6 added in *Mother's number of siblings* (q\_107b)
- 3 added in *Father's birth order* (q\_108a)
- 4 added in *Father's number of siblings* (q\_108b)
- 7 added in *Number of siblings* (q\_110a2)
- "farmer" removed in *Main Occupation* (q\_139)
- "ANTA" removed in centr\_id

## Changes to the patient ANTA-0021

- cannot convert value No to number in 70 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 32 questions: *Mother's birth order* (q\_107a), *Father's birth order* (q\_108a), *Father's number of siblings* (q\_108b), *Siblings' birth order* (q\_110a1), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 16 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_136, q\_137, q\_138
- cannot convert value Yes to number in q\_149d, q\_149h, q\_152h, q\_156h, q\_16a, q\_24c, q\_26a and q\_28a
- 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- 2 added in *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - Tumor* (q\_65a\_2), *Spinal cord MRI Thoracic - Tumor* (q\_65b\_2) and *Spinal cord MRI Lumbo-sacral - Tumor* (q\_65c\_2)

- Neurologist added in *First specialist who observed the patient* (q\_148), *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153), *What specialist 1 observed the patient* (q\_154b\_1) and *What specialist 2 observed the patient* (q\_154b\_2)
- factor variable q\_24, q\_26, q\_28 and q\_99.c1 doesn't have defined level Yes
- cannot convert value Normal to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2), *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7), *ALSFRS(1) 8. Walking* (q\_51\_1.8) and *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- After added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t) and *4th timing* (q\_48d\_t)
- cannot convert value None to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10), *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Did specialist 1 made diagnosis* (q\_154d\_1) and *Did specialist 2 made diagnosis* (q\_154d\_2)
- factor variable q\_16g and q\_30a doesn't have defined level No
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- cannot convert value Urban area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- "ANTC0008" added in *Control subject code* (q\_3b)
- factor variable *Ethnicity* (q\_7) doesn't have defined level Caucassian
- Lower limb replaces value Upper limb in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level Distal
- 1 Oro-facial added in *1st region* (q\_48a\_r)
- 2b Right Upper limb - proximal added in *2nd region* (q\_48b\_r)
- 2a Right Upper limb - distal added in *3rd region* (q\_48c\_r)
- 3b Left Upper limb - proximal added in *4th region* (q\_48d\_r)
- Lumbo-sacral removed in *Region3* (q\_50a)
- 2016-03-01 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value Normal speech processes to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value Normal eating habits to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value Slow or sloppy; all words are legible to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value Somewhat slow and clumsy, but no help needed to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value Independent and complete self-care with effort of decreased efficiency to number in *ALSFRS(1) 6.*

#### *Dressing and Hygiene* (q\_51\_1.6)

- NA replaces value NA in *ALSFERS(1) Rate of decay* (q\_51\_1.rate)
- No replaces value Yes in q\_63
- "Lithium" replaces value "Litium" in *Drug(s) used in psychiatric medication* (q\_89b)
- 2014-01-01 replaces value 1905-07-06 in *Date of initiation of Riluzole* (q\_91b)
- Wt/wt (normal) removed in q\_97a
- 10 added in *Mother's number of siblings* (q\_107b)
- 4 added in *Number of siblings* (q\_110a2)
- Head added in *Head/Neck trauma > 5 years* (q\_116)
- "Teacher" removed in *Main Occupation* (q\_139)
- "ANTA" removed in centr\_id

### Changes to the patient ANTA-0024

- cannot convert value No to number in 74 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 29 questions: *Siblings' birth order* (q\_110a1), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), *Brain MRI - Hypoxia* (q\_64\_6), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 16 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_136, q\_137, q\_138
- 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- 2 added in *Order of specialist 2 that observed the patient* (q\_154a\_2), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - Myelitis* (q\_65a\_4), *Spinal cord MRI Thoracic - Tumor* (q\_65b\_2) and *Spinal cord MRI Lumbo-sacral - Tumor* (q\_65c\_2)
- factor variable q\_24, q\_26, q\_28 and q\_99.c1 doesn't have defined level Yes
- cannot convert value Yes to number in q\_156h, q\_25b, q\_26b and q\_28b



- cannot convert value **Normal** to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2), *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5), *ALSFRS(1) 8. Walking* (q\_51\_1.8) and *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- 3 added in *Father's birth order* (q\_108a), *Number of siblings* (q\_110a2), *How long moderate sport activity 1* (q\_112a\_1c) and *How long moderate sport activity 2* (q\_112a\_2c)
- No added in *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), *Did specialist 1 made diagnosis* (q\_154d\_1) and *Did specialist 2 made diagnosis* (q\_154d\_2)
- After added in *2nd timing* (q\_48b\_t), *3rd timing* (q\_48c\_t) and *4th timing* (q\_48d\_t)
- cannot convert value **None** to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10), *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- Neurologist added in *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153) and *What specialist 2 observed the patient* (q\_154b\_2)
- factor variable q\_16g and q\_30a doesn't have defined level No
- Year of initiation of smoking (q\_88b) and Year of interruption of smoking (q\_88d) doesn't allow for tagged NA 2
- 4 added in *Mother's birth order* (q\_107a) and *Mother's number of siblings* (q\_107b)
- cannot convert value **Urban area** to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- Internal Medicine added in *First specialist who observed the patient* (q\_148) and *What specialist 1 observed the patient* (q\_154b\_1)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucasian**
- Lower limb replaces value **Upper limb** in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level **Distal**
- 2a Right Upper limb - distal added in *1st region* (q\_48a\_r)
- 2b Right Upper limb - proximal added in *2nd region* (q\_48b\_r)
- 1 Oro-facial added in *3rd region* (q\_48c\_r)
- 3b Left Upper limb - proximal added in *4th region* (q\_48d\_r)
- 2016-08-11 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value **Detectable speech disturbances** to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value **Normal eating habits** to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value **Slow or sloppy; all words are legible** to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value **Normal function** to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)

- cannot convert value **Somewhat slow and clumsy, but no help needed** to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- No replaces value **Yes** in q\_63
- Yes replaces value **No** in q\_89a
- "Lithium" added in *Drug(s) used in psychiatric medication* (q\_89b)
- 2016-01-01 replaces value 1905-07-08 in *Date of initiation of Riluzole* (q\_91b)
- Wt/wt (normal) removed in q\_97a
- 5 added in *Father's number of siblings* (q\_108b)
- Basketball added in *Type of moderate sport activity 1* (q\_112a\_1a)
- Fast walking added in *Type of moderate sport activity 2* (q\_112a\_2a)
- "teacher" removed in *Main Occupation* (q\_139)
- "ANTA" removed in *centr\_id*

## Changes to the patient ANTA-0052

- cannot convert value **No** to number in 64 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 27 questions: *Brain MRI - Tumor* (q\_64\_2), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), *Brain MRI - Hypoxia* (q\_64\_6), *Brain MRI - NA* (q\_64\_7), *Spinal cord MRI Cervical - Tumor* (q\_65a\_2), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 17 questions: q\_110d, q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, ... q\_136, q\_137, q\_138
- cannot convert value **Yes** to number in 14 questions: q\_149d, q\_152d, q\_152h, q\_156h, q\_16b, q\_24c, q\_25b, ... q\_28a, q\_28b, q\_28c
- 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- 2 added in *Mother's birth order* (q\_107a), *Number of children* (q\_110a), *Brain MRI - Normal* (q\_64\_1), *Spinal cord MRI Cervical - Normal* (q\_65a\_1), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)

- cannot convert value **Normal** to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4), *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5), *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7), *ALSFRS(1) 8. Walking* (q\_51\_1.8) and *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- factor variable q\_16g, q\_24, q\_26 and q\_30a doesn't have defined level **No**
- "Housewife" removed in *Main Occupation* (q\_139), *Main Occupation* (q\_140), *Second Occupation* (q\_141) and *Second Occupation* (q\_142)
- cannot convert value **None** to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10), *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- factor variable q\_28 and q\_99.c1 doesn't have defined level **Yes**
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- 7 added in *Mother's number of siblings* (q\_107b) and *Siblings' birth order* (q\_110a1)
- No added in *Head/Neck trauma in the last 5 years* (q\_115) and *Head/Neck trauma > 5 years* (q\_116)
- cannot convert value **Rural area** to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- **Antalya** added in *Medical facility* (facility\_id)
- **Hilmi Uysal** added in *Physician recording the data* (person\_id)
- 1975-06-20 replaces value 1962-06-20 in *Date of birth* (q\_5)
- factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucassian**
- **Upper and lower** replaces value **Lower limb** in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level **Distal**
- No replaces value **Yes** in q\_37
- **Bulbar** removed in *Region1* (q\_49a)
- **Lumbo-sacral** removed in *Region2* (q\_49b)
- factor variable *Region3* (q\_50a) doesn't have defined level **Cervical**
- 2017-06-23 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value **Speech combined with nonvocal communication** to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value **Slight but definite excess of saliva in mouth; may have nighttime drooling** to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2)
- cannot convert value **Early eating problems - occasional choking** to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value **Normal function** to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- **Wt/wt (normal)** removed in q\_97a
- **Father** added in *Which family member 1 had died* (q\_106\_1a)
- **Myocardial infarction** added in *What cause of death of family member*

- 1 (q\_106\_1b)
- 65 added in *Age of family member 1 at the moment of death* (q\_106\_1d)
- 3 added in *Father's birth order* (q\_108a)
- 5 added in *Father's number of siblings* (q\_108b)
- 8 added in *Number of siblings* (q\_110a2)
- NA removed in *Time gap between first-second specialist* (q\_151)
- "ANTA" removed in `centr_id`
- 27 replaces value 52 in `x`

## Changes to the patient ANTA-0053

- cannot convert value No to number in 71 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 29 questions: *Siblings' birth order* (q\_110a1), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Tumor* (q\_64\_2), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), *Brain MRI - Hypoxia* (q\_64\_6), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 20 questions: q\_110d, q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, ... q\_145, q\_146, q\_147
- cannot convert value Yes to number in q\_149h, q\_156h, q\_27a, q\_27c, q\_29a, q\_29b and q\_29c
- 2 added in *Mother's birth order* (q\_107a), *Number of siblings* (q\_110a2), *Brain MRI - Normal* (q\_64\_1), *Spinal cord MRI Cervical - Normal* (q\_65a\_1), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)
- 0 added in *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- factor variable q\_16g, q\_24, q\_26 and q\_30a doesn't have defined level No
- cannot convert value Normal to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2), *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5) and *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value None to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10), *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1)*

12. *Respiratory insufficiency* (q\_51\_1.12)

- **Neurologist** added in *First specialist who observed the patient* (q\_148), *Specialist who made the diagnosis* (q\_153) and *What specialist 1 observed the patient* (q\_154b\_1)
- factor variable **q\_28** and **q\_99.c1** doesn't have defined level **Yes**
- **3** added in *Mother's number of siblings* (q\_107b) and *Father's birth order* (q\_108a)
- **No** added in *Head/Neck trauma in the last 5 years* (q\_115) and *Head/Neck trauma > 5 years* (q\_116)
- cannot convert value **Urban area** to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- **Antalya** added in *Medical facility* (facility\_id)
- **Hilmi Uysal** added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucassian**
- **Upper and lower** replaces value **Lower limb** in *Limb onset* (q\_18a)
- **Distal and proximal** replaces value **Proximal** in *Predominant impairment* (q\_18c)
- **Lumbo-sacral** removed in *Region1* (q\_49a)
- **Cervical** removed in *Region2* (q\_49b)
- **2017-06-23** added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value **Normal speech processes** to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value **Normal eating habits** to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value **Slow or sloppy; all words are legible** to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value **Independent and complete self-care with effort of decreased efficiency** to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value **Walks with assistance** to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value **Needs assistance** to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- **NA** replaces value **NA** in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- *Year of interruption of smoking* (q\_88d) doesn't allow for tagged **NA 2**
- **"Fluoxetine"** replaces value **"FLUOXETINE"** in *Drug(s) used in psychiatric medication* (q\_89b)
- **2018-02-20** added in *Date of initiation of Riluzole* (q\_91b)
- **Wt/wt (normal)** removed in q\_97a
- **Father** added in *Which family member 1 had a history of other severe disease* (q\_105\_1a)
- **Cancer lung** added in *What severe disease family member 1 had* (q\_105\_1b)
- **Mother** added in *Which family member 2 had a history of other severe disease* (q\_105\_2a)
- **other** added in *What severe disease family member 2 had* (q\_105\_2b)

- "stroke" added in *What other severe disease family member 2 had* (q\_105\_2c)
- 4 added in *Father's number of siblings* (q\_108b)
- "GRAPHIC DESIGNER" removed in *Main Occupation* (q\_139)
- Large town- > 100 000 removed in *Place of living* (q\_144)
- NA removed in *Time gap between first-second specialist* (q\_151)
- Yes added in *Did specialist 1 made diagnosis* (q\_154d\_1)
- "ANTA" removed in *centr\_id*
- 28 replaces value 53 in *x*

## Changes to the patient ANTA-0056

- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- cannot convert value No to number in 57 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- 1 added in 28 questions: *Siblings' birth order* (q\_110a1), *Brain MRI - Tumor* (q\_64\_2), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), *Brain MRI - Hypoxia* (q\_64\_6), *Brain MRI - NA* (q\_64\_7), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- cannot convert value Yes to number in 21 questions: q\_149d, q\_149e, q\_149f, q\_149g, q\_149h, q\_152d, q\_152e, ... q\_29a, q\_29b, q\_29c
- No removed in 17 questions: q\_110d, q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, ... q\_136, q\_137, q\_138
- 2 added in *Mother's birth order* (q\_107a), *Father's birth order* (q\_108a), *Number of children* (q\_110a), *Brain MRI - Normal* (q\_64\_1), *Spinal cord MRI Cervical - Normal* (q\_65a\_1), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)
- 0 added in *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- factor variable q\_16g, q\_24, q\_28 and q\_30a doesn't have defined level No
- "farmer" removed in *Main Occupation* (q\_139), *Main Occupation* (q\_140), *Second Occupation* (q\_141) and *Second Occupation* (q\_142)
- factor variable q\_26 and q\_99.c1 doesn't have defined level Yes
- cannot convert value None to number in *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)

- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- 3 added in *Father's number of siblings* (q\_108b) and *Number of siblings* (q\_110a2)
- No added in *Head/Neck trauma in the last 5 years* (q\_115) and *Head/Neck trauma > 5 years* (q\_116)
- cannot convert value **Rural area** to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- **Neurologist** added in *First specialist who observed the patient* (q\_148) and *Second specialist who observed the patient* (q\_150)
- **Antalya** added in *Medical facility* (facility\_id)
- **Hilmi Uysal** added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucassian**
- **Lower limb** replaces value **Upper limb** in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level **Distal**
- **Cervical** removed in *Region1* (q\_49a)
- **Lumbo-sacral** removed in *Region2* (q\_49b)
- **Thoracic** removed in *Region3* (q\_50a)
- 2017-06-24 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value **Normal speech processes** to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value **Normal** to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2)
- cannot convert value **Normal eating habits** to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value **Able to grip pen but unable to write** to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value **Can cut most foods, although clumsy and slow; some help needed** to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value **Total dependence** to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value **Can initiate, but not turn or adjust sheets alone** to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value **Early ambulation difficulties** to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value **Needs assistance** to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- cannot convert value **Occurs at rest Shortness of breath at rest, difficulty breathing when either sitting or lying** to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- **Wt/wt (normal)** removed in q\_97a

- 8 added in *Mother's number of siblings* (q\_107b)
- No replaces value **Yes** in q\_145
- "ANTA" removed in **centr\_id**
- 31 replaces value 56 in **x**

## Changes to the patient ANTA-0057

- cannot convert value **No** to number in 62 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 31 questions: *Mother's birth order* (q\_107a), *Father's birth order* (q\_108a), *Siblings' birth order* (q\_110a1), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Tumor* (q\_64\_2), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- cannot convert value **Yes** to number in 16 questions: q\_149f, q\_149g, q\_152d, q\_152e, q\_152f, q\_152g, q\_152h, ... q\_28b, q\_29a, q\_29b
- No removed in 15 questions: q\_110d, q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, ... q\_135, q\_136, q\_138
- 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- factor variable q\_134, q\_137, q\_28, q\_30a and q\_99.c1 doesn't have defined level **Yes**
- 2 added in *Number of siblings* (q\_110a2), *Brain MRI - Normal* (q\_64\_1), *Spinal cord MRI Cervical - Normal* (q\_65a\_1), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)
- "mechanical engineer" removed in *Main Occupation* (q\_139), *Main Occupation* (q\_140), *Second Occupation* (q\_141) and *Second Occupation* (q\_142)
- factor variable q\_16g, q\_24 and q\_26 doesn't have defined level **No**
- cannot convert value **None** to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10), *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- **Neurologist** added in *First specialist who observed the patient* (q\_148), *Second specialist who observed the patient* (q\_150) and *What specialist 1 observed the patient* (q\_154b\_1)
- cannot convert value **Normal** to number in *ALSFRS(1) 2. Salivation*



- (q\_51\_1.2) and *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- No added in *Head/Neck trauma in the last 5 years* (q\_115) and *Head/Neck trauma > 5 years* (q\_116)
- cannot convert value **Urban area** to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- **Antalya** added in *Medical facility* (facility\_id)
- **Hilmi Uysal** added in *Physician recording the data* (person\_id)
- 1026-09-23 replaces value 2016-09-23 in *Date of consultation* (q\_4)
- factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucassian**
- **Upper and lower** replaces value **Lower limb** in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level **Distal**
- **Lumbo-sacral** removed in *Region1* (q\_49a)
- **Cervical** removed in *Region2* (q\_49b)
- 2017-06-24 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value **Normal speech processes** to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value **Normal eating habits** to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value **Slow or sloppy; all words are legible** to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value **Independent and complete self-care with effort of decreased efficiency** to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value **Somewhat slow and clumsy, but no help needed** to number in *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value **Walks with assistance** to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- cannot convert value **Mild unsteadiness or fatigue** to number in *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- **NA** replaces value **NA** in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- **Wt/wt (normal)** removed in q\_97a
- **Father** added in *Which family member 1 had died* (q\_106\_1a)
- **other** added in *What cause of death of family member 1* (q\_106\_1b)
- **"UNKNOWN"** added in *What other cause of death of family member 1* (q\_106\_1c)
- **67** added in *Age of family member 1 at the moment of death* (q\_106\_1d)
- **4** added in *Mother's number of siblings* (q\_107b)
- **3** added in *Father's number of siblings* (q\_108b)
- **Yes** added in *Did specialist 1 made diagnosis* (q\_154d\_1)
- **"ANTA"** removed in centr\_id
- **32** replaces value **57** in x

## Changes to the patient ANTA-0058

- cannot convert value **No** to number in 77 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 29 questions: *Lives in Rural Area/Urban* (q\_143a), *Lives in Rural Area/Urban* (q\_144a), *Brain MRI - Tumor* (q\_64\_2), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), *Brain MRI - Hypoxia* (q\_64\_6), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 20 questions: q\_110d, q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, ... q\_145, q\_146, q\_147
- 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- 2 added in *Number of children* (q\_110a), *Siblings' birth order* (q\_110a1), *Brain MRI - Normal* (q\_64\_1), *Spinal cord MRI Cervical - Normal* (q\_65a\_1), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)
- cannot convert value **Normal** to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2), *ALSFRS(1) 4. Handwriting* (q\_51\_1.4), *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5), *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7) and *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- factor variable q\_16g, q\_24, q\_26 and q\_30a doesn't have defined level **No**
- cannot convert value **None** to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10), *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- **Neurologist** added in *First specialist who observed the patient* (q\_148), *Second specialist who observed the patient* (q\_150) and *Specialist who made the diagnosis* (q\_153)
- factor variable q\_28 and q\_99.c1 doesn't have defined level **Yes**
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- 3 added in *Mother's birth order* (q\_107a) and *Father's birth order* (q\_108a)
- No added in *Head/Neck trauma in the last 5 years* (q\_115) and *Head/Neck*

*trauma* > 5 years (q\_116)

- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level *Caucassian*
- cannot convert value *Yes* to number in q\_16a
- *Upper* and *lower* replaces value *Lower limb* in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level *Distal*
- *Cervical* removed in *Region1* (q\_49a)
- *Lumbo-sacral* removed in *Region2* (q\_49b)
- 2017-06-24 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value *Normal speech processes* to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value *Normal eating habits* to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value *Normal function* to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value *Early ambulation difficulties* to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- *Wt/wt (normal)* removed in q\_97a
- 8 added in *Mother's number of siblings* (q\_107b)
- 11 added in *Father's number of siblings* (q\_108b)
- 7 added in *Number of siblings* (q\_110a2)
- "ANTA" removed in *centr\_id*
- 33 replaces value 58 in *x*

## Changes to the patient ANTA-0060

- cannot convert value *No* to number in 69 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 27 questions: *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), *Brain MRI - Hypoxia* (q\_64\_6), *Brain MRI - NA* (q\_64\_7), *Spinal cord MRI Cervical - Normal* (q\_65a\_1), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)

- No removed in 20 questions: q\_110d, q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, ... q\_145, q\_146, q\_147
- cannot convert value Yes to number in q\_149a, q\_149h, q\_152h, q\_156h, q\_16a, q\_24c, q\_26a, q\_26b and q\_26c
- 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- cannot convert value Normal to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2), *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5), *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7), *ALSFRS(1) 8. Walking* (q\_51\_1.8) and *ALSFRS(1) 9. Climbing Stairs* (q\_51\_1.9)
- 2 added in *Number of children* (q\_110a), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - NA* (q\_65a\_8), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)
- factor variable q\_16g, q\_24, q\_28 and q\_30a doesn't have defined level No
- cannot convert value None to number in *ALSFRS(1) 10. Dyspnea* (q\_51\_1.10), *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- 3 added in *Mother's birth order* (q\_107a), *Father's birth order* (q\_108a) and *Siblings' birth order* (q\_110a1)
- 6 added in *Mother's number of siblings* (q\_107b), *Father's number of siblings* (q\_108b) and *Number of siblings* (q\_110a2)
- Neurologist added in *First specialist who observed the patient* (q\_148), *Second specialist who observed the patient* (q\_150) and *Specialist who made the diagnosis* (q\_153)
- factor variable q\_26 and q\_99.c1 doesn't have defined level Yes
- Stroke - type unknown added in *What severe disease family member 1 had* (q\_105\_1b) and *What cause of death of family member 1* (q\_106\_1b)
- No added in *Head/Neck trauma in the last 5 years* (q\_115) and *Head/Neck trauma > 5 years* (q\_116)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- factor variable Ethnicity (q\_7) doesn't have defined level Caucassian
- Lower limb replaces value Upper limb in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level Distal
- Cervical removed in *Region1* (q\_49a)
- Lumbo-sacral removed in *Region2* (q\_49b)
- Thoracic removed in *Region3* (q\_50a)
- 2017-06-25 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value Intelligible with repeating to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value Normal eating habits to number in *ALSFRS(1) 3.*

*Swallowing* (q\_51\_1.3)

- cannot convert value **Slow or sloppy**; all words are legible to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value **Normal function** to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- 2016 replaces value NA in *Year of interruption of smoking* (q\_88d)
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- **Wt/wt (normal)** removed in q\_97a
- **Mother** added in *Which family member 1 had a history of other severe disease* (q\_105\_1a)
- **Father** added in *Which family member 1 had died* (q\_106\_1a)
- 53 added in *Age of family member 1 at the moment of death* (q\_106\_1d)
- cannot convert value **Urban area** to number in *Lives in Rural Area/Urban* (q\_143a)
- cannot convert value **Rural area** to number in *Lives in Rural Area/Urban* (q\_144a)
- "ANTA" removed in **centr\_id**
- 35 replaces value 60 in **x**

## Changes to the patient ANTA-0061

- cannot convert value **No** to number in 66 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 59 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 30 questions: *Mother's birth order* (q\_107a), *Mother's number of siblings* (q\_107b), *Order of specialist 1 that observed the patient* (q\_154a\_1), *Brain MRI - Normal* (q\_64\_1), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 17 questions: q\_110d, q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, ... q\_136, q\_137, q\_138
- cannot convert value **Yes** to number in 12 questions: q\_149d, q\_149e, q\_152h, q\_156h, q\_16a, q\_26a, q\_26b, ... q\_27b, q\_28a, q\_28c
- 0 added in *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)

- 2 added in *Number of children* (q\_110a), *Brain MRI - Tumor* (q\_64\_2), *Spinal cord MRI Cervical - NA* (q\_65a\_8), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)
- factor variable q\_16g, q\_24, q\_28 and q\_30a doesn't have defined level No
- "Housewife" removed in *Main Occupation* (q\_139), *Main Occupation* (q\_140), *Second Occupation* (q\_141) and *Second Occupation* (q\_142)
- Neurologist added in *First specialist who observed the patient* (q\_148), *Second specialist who observed the patient* (q\_150), *Specialist who made the diagnosis* (q\_153) and *What specialist 1 observed the patient* (q\_154b\_1)
- factor variable q\_26 and q\_99.c1 doesn't have defined level Yes
- cannot convert value Normal to number in *ALSFRS(1) 2. Salivation* (q\_51\_1.2) and *ALSFRS(1) 7. Turning in Bed and Adjusting Bed Clothes* (q\_51\_1.7)
- cannot convert value None to number in *ALSFRS(1) 11. Orthopnea* (q\_51\_1.11) and *ALSFRS(1) 12. Respiratory insufficiency* (q\_51\_1.12)
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- 4 added in *Father's birth order* (q\_108a) and *Number of siblings* (q\_110a2)
- No added in *Head/Neck trauma in the last 5 years* (q\_115) and *Head/Neck trauma > 5 years* (q\_116)
- cannot convert value Rural area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level Caucasian
- Lower limb replaces value Upper limb in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level Distal
- Cervical removed in *Region1* (q\_49a)
- Lumbo-sacral removed in *Region2* (q\_49b)
- Thoracic removed in *Region3* (q\_50a)
- 2017-06-25 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- cannot convert value Normal speech processes to number in *ALSFRS(1) 1. Speech* (q\_51\_1.1)
- cannot convert value Normal eating habits to number in *ALSFRS(1) 3. Swallowing* (q\_51\_1.3)
- cannot convert value Slow or sloppy; all words are legible to number in *ALSFRS(1) 4. Handwriting* (q\_51\_1.4)
- cannot convert value Can cut most foods, although clumsy and slow; some help needed to number in *ALSFRS(1) 5. Cutting Food and Handling Utensils* (q\_51\_1.5)
- cannot convert value Independent and complete self-care with effort of decreased efficiency to number in *ALSFRS(1) 6. Dressing and Hygiene* (q\_51\_1.6)
- cannot convert value Early ambulation difficulties to number in *ALSFRS(1) 8. Walking* (q\_51\_1.8)

- cannot convert value **Mild unsteadiness** or **fatigue** to number in *ALSFERS(1) 9. Climbing Stairs* (q\_51\_1.9)
- cannot convert value **Occurs when walking** to number in *ALSFERS(1) 10. Dyspnea* (q\_51\_1.10)
- 40 removed in *ALSFERS-R total* (q\_51\_1.score)
- NA replaces value NA in *ALSFERS(1) Rate of decay* (q\_51\_1.rate)
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- 5 added in *Father's number of siblings* (q\_108b)
- 3 added in *Siblings' birth order* (q\_110a1)
- Yes added in *Did specialist 1 made diagnosis* (q\_154d\_1)
- "ANTA" removed in *centr\_id*
- 36 replaces value 61 in *x*

## Changes to the patient ANTA-0059

- cannot convert value **No** to number in 78 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_38.1b, q\_38.2a, q\_38.2b
- NA added in 71 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- 1 added in 29 questions: *Lives in Rural Area/Urban* (q\_143a), *Lives in Rural Area/Urban* (q\_144a), *Brain MRI - Tumor* (q\_64\_2), *Brain MRI - Stroke* (q\_64\_3), *Brain MRI - Multiple Sclerosis* (q\_64\_4), *Brain MRI - Trauma* (q\_64\_5), *Brain MRI - Hypoxia* (q\_64\_6), ... *Spinal cord MRI Lumbo-sacral - Syringomyelia* (q\_65c\_6), *Spinal cord MRI Lumbo-sacral - Other* (q\_65c\_7), *Spinal cord MRI Lumbo-sacral - NA* (q\_65c\_8)
- No removed in 20 questions: q\_110d, q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, ... q\_145, q\_146, q\_147
- 0 added in *Cognition - ECAS value (or NF, NA, NR)* (q\_45a), *Cognition - ECAS lower range* (q\_45b), *Cognition - ECAS upper range* (q\_45c), *ALS depression inventory value (or NF, NA, NR)* (q\_47a), *ALS depression inventory upper range* (q\_47b), *ALS depression inventory lower range* (q\_47c) and *Mean number of packs/day* (q\_88e)
- factor variable q\_16g, q\_24, q\_28 and q\_30a doesn't have defined level No
- 2 added in *Brain MRI - Normal* (q\_64\_1), *Spinal cord MRI Cervical - Normal* (q\_65a\_1), *Spinal cord MRI Thoracic - Normal* (q\_65b\_1) and *Spinal cord MRI Lumbo-sacral - Normal* (q\_65c\_1)
- factor variable q\_26 and q\_99.c1 doesn't have defined level Yes
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- No added in *Head/Neck trauma in the last 5 years* (q\_115) and *Head/Neck trauma > 5 years* (q\_116)

- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- factor variable *Ethnicity* (q\_7) doesn't have defined level *Caucassian*
- *Lower limb* replaces value *Upper limb* in *Limb onset* (q\_18a)
- factor variable *Predominant impairment* (q\_18c) doesn't have defined level *Distal*
- *Cervical* removed in *Region1* (q\_49a)
- *Lumbo-sacral* removed in *Region2* (q\_49b)
- 2017-06-25 added in *ALSFRS(1) Acquisition date* (q\_51\_1.date)
- NA replaces value NA in *ALSFRS(1) Rate of decay* (q\_51\_1.rate)
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- Yes replaces value No in q\_96a
- "ghj" added in *Immunosuppressor's name* (q\_96b)
- *Wt/wt (normal)* removed in q\_97a
- "ANTA" removed in *centr\_id*
- 34 replaces value 59 in *x*

## Changes to the patient ANTC0001

- NA added in 152 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- cannot convert value No to number in 24 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_144c, q\_144d, q\_144e
- No added in 16 questions: *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), q\_19, q\_20, q\_21, q\_30, q\_31, ... q\_40, q\_41, q\_63
- No removed in 15 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_135, q\_136, q\_138
- 1 added in q\_38.1a, q\_38.1b, q\_38.2a and q\_38.2b
- factor variable q\_137 and q\_99.c1 doesn't have defined level *Yes*
- 6 added in *Mother's number of siblings* (q\_107b) and *Father's number of siblings* (q\_108b)
- "No" removed in *Second Occupation* (q\_141) and *Second Occupation* (q\_142)
- cannot convert value *Urban area* to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- "ANTC0001" replaces value "ANTA0001" in *Control subject code* (q\_3b)
- 2016-01-11 replaces value 2086-01-12 in *Date of consultation* (q\_4)
- 1974-04-23 replaces value 2044-04-24 in *Date of birth* (q\_5)



- factor variable *Ethnicity* (q\_7) doesn't have defined level *Caucassian*
- *None* added in *Which cognitive symptoms at onset* (q\_22)
- *Right* added in *Handedness* (q\_23)
- *Positive* added in q\_43
- 1996 replaces value NA in *Year of initiation of smoking* (q\_88b)
- *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- 0 added in *Mean number of packs/day* (q\_88e)
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- 5 added in *Mother's birth order* (q\_107a)
- 4 added in *Father's birth order* (q\_108a)
- "Housewife" removed in *Main Occupation* (q\_139)
- "ANTC" removed in *centr\_id*
- 37 replaces value 571 in *x*

## Changes to the patient ANTC0002

- NA added in 152 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- cannot convert value No to number in 24 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_144c, q\_144d, q\_144e
- No removed in 19 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_145, q\_146, q\_147
- No added in 16 questions: *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), q\_19, q\_20, q\_21, q\_30, q\_31, ... q\_40, q\_41, q\_63
- 1 added in *Father's birth order* (q\_108a), *Father's number of siblings* (q\_108b), *Siblings' birth order* (q\_110a1), q\_38.1a, q\_38.1b, q\_38.2a and q\_38.2b
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- "no" removed in *Second Occupation* (q\_141) and *Second Occupation* (q\_142)
- *Large town- > 100 000* removed in *Place of living* (q\_143) and *Place of living* (q\_144)
- cannot convert value *Urban area* to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- *Antalya* added in *Medical facility* (facility\_id)
- *Hilmi Uysal* added in *Physician recording the data* (person\_id)
- 2016-01-01 replaces value 2086-01-02 in *Date of consultation* (q\_4)
- 1950-04-02 replaces value 2020-04-03 in *Date of birth* (q\_5)
- factor variable *Ethnicity* (q\_7) doesn't have defined level *Caucassian*

- None added in *Which cognitive symptoms at onset* (q\_22)
- Right added in *Handedness* (q\_23)
- Positive added in q\_43
- Type II replaces value Type I in q\_74
- 0 added in *Mean number of packs/day* (q\_88e)
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- factor variable q\_99.c1 doesn't have defined level Yes
- 2 added in *Mother's birth order* (q\_107a)
- 4 added in *Mother's number of siblings* (q\_107b)
- 5 added in *Number of siblings* (q\_110a2)
- Yes removed in q\_111
- "cook" removed in *Main Occupation* (q\_139)
- "ANTC" removed in *centr\_id*
- 38 replaces value 572 in *x*

## Changes to the patient ANTC0003

- NA added in 152 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- cannot convert value No to number in 24 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_144c, q\_144d, q\_144e
- No added in 16 questions: *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), q\_19, q\_20, q\_21, q\_30, q\_31, ... q\_40, q\_41, q\_63
- No removed in 16 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_136, q\_137, q\_138
- 1 added in *Father's birth order* (q\_108a), q\_38.1a, q\_38.1b, q\_38.2a and q\_38.2b
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- 7 added in *Father's number of siblings* (q\_108b) and *Number of siblings* (q\_110a2)
- "Farmer" removed in *Main Occupation* (q\_140) and *Second Occupation* (q\_141)
- cannot convert value Urban area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- 2016-05-26 replaces value 2086-05-28 in *Date of consultation* (q\_4)
- 1959-11-02 replaces value 2029-11-03 in *Date of birth* (q\_5)
- factor variable *Ethnicity* (q\_7) doesn't have defined level Caucasian

- None added in *Which cognitive symptoms at onset* (q\_22)
- Right added in *Handedness* (q\_23)
- Positive added in q\_43
- 0 added in *Mean number of packs/day* (q\_88e)
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- factor variable q\_99.c1 doesn't have defined level Yes
- 2 added in *Mother's birth order* (q\_107a)
- 5 added in *Mother's number of siblings* (q\_107b)
- 4 added in *Siblings' birth order* (q\_110a1)
- "Housewife" removed in *Main Occupation* (q\_139)
- "ANTC" removed in *centr\_id*
- 39 replaces value 573 in *x*

## Changes to the patient ANTC0004

- NA added in 152 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- cannot convert value No to number in 24 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_144c, q\_144d, q\_144e
- No added in 16 questions: *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), q\_19, q\_20, q\_21, q\_30, q\_31, ... q\_40, q\_41, q\_63
- No removed in 16 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_136, q\_137, q\_138
- 1 added in q\_38.1a, q\_38.1b, q\_38.2a and q\_38.2b
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- 3 added in *Mother's number of siblings* (q\_107b) and *Father's birth order* (q\_108a)
- cannot convert value Rural area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- 2016-05-02 replaces value 2086-05-04 in *Date of consultation* (q\_4)
- 1971-07-21 replaces value 2041-07-22 in *Date of birth* (q\_5)
- factor variable *Ethnicity* (q\_7) doesn't have defined level Caucasian
- None added in *Which cognitive symptoms at onset* (q\_22)
- Right added in *Handedness* (q\_23)
- Positive added in q\_43
- 0 added in *Mean number of packs/day* (q\_88e)
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)

- factor variable `q_99.c1` doesn't have defined level **Yes**
- 2 added in *Mother's birth order* (`q_107a`)
- 6 added in *Father's number of siblings* (`q_108b`)
- 4 added in *Siblings' birth order* (`q_110a1`)
- 8 added in *Number of siblings* (`q_110a2`)
- "Housewife" removed in *Main Occupation* (`q_139`)
- "ANTC" removed in `centr_id`
- 40 replaces value 574 in `x`

## Changes to the patient ANTC0005

- NA added in 152 questions: *Regular specific diet - No* (`q_114a`), *Regular specific diet - Mediterranean* (`q_114b`), *Regular specific diet - Vegetarian* (`q_114c`), *Regular specific diet - Vegan* (`q_114d`), *Regular specific diet - Gluten-free* (`q_114e`), *Regular specific diet - High protein* (`q_114f`), *Regular specific diet - Low carbohydrate* (`q_114g`), ... *Metastasis - Colon* (`q_85b_7`), *Metastasis - Rectum* (`q_85b_8`), *Metastasis - other Abdominal* (`q_85b_9`)
- cannot convert value No to number in 24 questions: `q_117a`, `q_117b`, `q_117c`, `q_118a`, `q_118b`, `q_118c`, `q_119a`, ... `q_144c`, `q_144d`, `q_144e`
- No added in 16 questions: *Head/Neck trauma in the last 5 years* (`q_115`), *Head/Neck trauma > 5 years* (`q_116`), `q_19`, `q_20`, `q_21`, `q_30`, `q_31`, ... `q_40`, `q_41`, `q_63`
- No removed in 15 questions: `q_123`, `q_124`, `q_125`, `q_126`, `q_127`, `q_128`, `q_129`, ... `q_135`, `q_136`, `q_138`
- 1 added in *Siblings' birth order* (`q_110a1`), `q_38.1a`, `q_38.1b`, `q_38.2a` and `q_38.2b`
- 3 added in *Mother's birth order* (`q_107a`), *Father's birth order* (`q_108a`) and *Number of siblings* (`q_110a2`)
- *Year of initiation of smoking* (`q_88b`) and *Year of interruption of smoking* (`q_88d`) doesn't allow for tagged NA 2
- factor variable `q_137` and `q_99.c1` doesn't have defined level **Yes**
- cannot convert value **Urban area** to number in *Lives in Rural Area/Urban* (`q_143a`) and *Lives in Rural Area/Urban* (`q_144a`)
- Antalya added in *Medical facility* (`facility_id`)
- Hilmi Uysal added in *Physician recording the data* (`person_id`)
- 2016-02-01 replaces value 2086-02-02 in *Date of consultation* (`q_4`)
- 1968-11-15 replaces value 2038-11-17 in *Date of birth* (`q_5`)
- factor variable *Ethnicity* (`q_7`) doesn't have defined level **Caucassian**
- **None** added in *Which cognitive symptoms at onset* (`q_22`)
- **Right** added in *Handedness* (`q_23`)
- **Positive** added in `q_43`
- 0 added in *Mean number of packs/day* (`q_88e`)
- 2018-02-20 added in *Date of initiation of Riluzole* (`q_91b`)
- 8 added in *Mother's number of siblings* (`q_107b`)
- 7 added in *Father's number of siblings* (`q_108b`)

- "Cook" removed in *Main Occupation* (q\_139)
- "Housewife" removed in *Main Occupation* (q\_140)
- "ANTC" removed in *centr\_id*
- 41 replaces value 575 in *x*

## Changes to the patient ANTC0006

- NA added in 152 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- cannot convert value No to number in 24 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_144c, q\_144d, q\_144e
- No added in 16 questions: *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), q\_19, q\_20, q\_21, q\_30, q\_31, ... q\_40, q\_41, q\_63
- No removed in 16 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_136, q\_137, q\_138
- 1 added in *Mother's birth order* (q\_107a), *Father's birth order* (q\_108a), *Lives in Rural Area/Urban* (q\_143a), *Lives in Rural Area/Urban* (q\_144a), q\_38.1a, q\_38.1b, q\_38.2a and q\_38.2b
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- 2016-04-21 replaces value 2086-04-23 in *Date of consultation* (q\_4)
- 1970-01-01 added in *Date of birth* (q\_5)
- factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucassian**
- None added in *Which cognitive symptoms at onset* (q\_22)
- Right added in *Handedness* (q\_23)
- Positive added in q\_43
- 0 added in *Mean number of packs/day* (q\_88e)
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- factor variable q\_99.c1 doesn't have defined level **Yes**
- 3 added in *Mother's number of siblings* (q\_107b)
- 5 added in *Father's number of siblings* (q\_108b)
- 6 added in *Siblings' birth order* (q\_110a1)
- 7 added in *Number of siblings* (q\_110a2)
- "ANTC" removed in *centr\_id*
- 42 replaces value 576 in *x*

## Changes to the patient ANTC0007

- NA added in 152 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- cannot convert value No to number in 24 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_144c, q\_144d, q\_144e
- No added in 16 questions: *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), q\_19, q\_20, q\_21, q\_30, q\_31, ... q\_40, q\_41, q\_63
- No removed in 16 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_136, q\_137, q\_138
- 1 added in *Mother's birth order* (q\_107a), q\_38.1a, q\_38.1b, q\_38.2a and q\_38.2b
- *Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- 3 added in *Father's birth order* (q\_108a) and *Father's number of siblings* (q\_108b)
- cannot convert value Urban area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- 2016-01-01 replaces value 2086-01-02 in *Date of consultation* (q\_4)
- 1960-05-01 replaces value 2030-05-03 in *Date of birth* (q\_5)
- factor variable *Ethnicity* (q\_7) doesn't have defined level Caucassian
- None added in *Which cognitive symptoms at onset* (q\_22)
- Right added in *Handedness* (q\_23)
- Positive added in q\_43
- 0 added in *Mean number of packs/day* (q\_88e)
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- factor variable q\_99.c1 doesn't have defined level Yes
- 11 added in *Mother's number of siblings* (q\_107b)
- "Housewife" removed in *Main Occupation* (q\_139)
- "ANTC" removed in centr\_id
- 43 replaces value 577 in x

## Changes to the patient ANTC0008

- NA added in 152 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular*

- specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- cannot convert value No to number in 24 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_144c, q\_144d, q\_144e
- No removed in 19 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_145, q\_146, q\_147
- No added in 16 questions: *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), q\_19, q\_20, q\_21, q\_30, q\_31, ... q\_40, q\_41, q\_63
- 1 added in q\_38.1a, q\_38.1b, q\_38.2a and q\_38.2b
- Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- 4 added in *Mother's birth order* (q\_107a) and *Father's number of siblings* (q\_108b)
- 2 added in *Father's birth order* (q\_108a) and *Siblings' birth order* (q\_110a1)
- 3 added in *Number of siblings* (q\_110a2) and *How long moderate sport activity 1* (q\_112a\_1c)
- Large town- > 100 000 removed in *Place of living* (q\_143) and *Place of living* (q\_144)
- cannot convert value Urban area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- 2016-02-10 replaces value 2086-02-11 in *Date of consultation* (q\_4)
- 1975-10-03 replaces value 2045-10-04 in *Date of birth* (q\_5)
- factor variable *Ethnicity* (q\_7) doesn't have defined level Caucassian
- None added in *Which cognitive symptoms at onset* (q\_22)
- Right added in *Handedness* (q\_23)
- Positive added in q\_43
- 0 added in *Mean number of packs/day* (q\_88e)
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- factor variable q\_99.c1 doesn't have defined level Yes
- 6 added in *Mother's number of siblings* (q\_107b)
- Fast walking added in *Type of moderate sport activity 1* (q\_112a\_1a)
- "Tourism" removed in *Main Occupation* (q\_139)
- "Insurer" removed in *Main Occupation* (q\_140)
- "ANTC" removed in centr\_id
- 44 replaces value 578 in x

## Changes to the patient ANTC0009

- NA added in 152 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet -*

- Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- cannot convert value No to number in 24 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_144c, q\_144d, q\_144e
- No added in 16 questions: *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), q\_19, q\_20, q\_21, q\_30, q\_31, ... q\_40, q\_41, q\_63
- No removed in 16 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ... q\_136, q\_137, q\_138
- 1 added in *Father's birth order* (q\_108a), *Father's number of siblings* (q\_108b), *Lives in Rural Area/Urban* (q\_143a), *Lives in Rural Area/Urban* (q\_144a), q\_38.1a, q\_38.1b, q\_38.2a and q\_38.2b
- Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- 4 added in *Mother's birth order* (q\_107a) and *Mother's number of siblings* (q\_107b)
- 5 added in *Siblings' birth order* (q\_110a1) and *Number of siblings* (q\_110a2)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- 2016-02-26 replaces value 2086-02-27 in *Date of consultation* (q\_4)
- 1959-01-01 replaces value 2029-01-02 in *Date of birth* (q\_5)
- factor variable *Ethnicity* (q\_7) doesn't have defined level *Caucassian*
- None* added in *Which cognitive symptoms at onset* (q\_22)
- Right* added in *Handedness* (q\_23)
- Positive* added in q\_43
- 0 added in *Mean number of packs/day* (q\_88e)
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- factor variable q\_99.c1 doesn't have defined level *Yes*
- "ANTC" removed in *centr\_id*
- 45 replaces value 579 in *x*

## Changes to the patient ANTC0010

- NA added in 152 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- cannot convert value No to number in 24 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_144c, q\_144d, q\_144e
- No added in 16 questions: *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), q\_19, q\_20, q\_21, q\_30, q\_31,



- ...q\_40, q\_41, q\_63
- No removed in 16 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ...q\_136, q\_137, q\_138
- 1 added in *Siblings' birth order* (q\_110a1), *Lives in Rural Area/Urban* (q\_143a), *Lives in Rural Area/Urban* (q\_144a), q\_38.1a, q\_38.1b, q\_38.2a and q\_38.2b
- Year of initiation of smoking* (q\_88b) and *Year of interruption of smoking* (q\_88d) doesn't allow for tagged NA 2
- 5 added in *Mother's birth order* (q\_107a) and *Number of siblings* (q\_110a2)
- 4 added in *Father's number of siblings* (q\_108b) and *Number of children* (q\_110a)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- 2016-08-12 replaces value 2086-08-14 in *Date of consultation* (q\_4)
- 1974-05-04 replaces value 2044-05-05 in *Date of birth* (q\_5)
- factor variable *Ethnicity* (q\_7) doesn't have defined level *Caucassian*
- None added in *Which cognitive symptoms at onset* (q\_22)
- Right added in *Handedness* (q\_23)
- Positive added in q\_43
- 0 added in *Mean number of packs/day* (q\_88e)
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- factor variable q\_99.c1 doesn't have defined level *Yes*
- 10 added in *Mother's number of siblings* (q\_107b)
- 3 added in *Father's birth order* (q\_108a)
- "ANTC" removed in centr\_id
- 46 replaces value 580 in x

## Changes to the patient ANTC0011

- NA added in 152 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- cannot convert value No to number in 23 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ...q\_144c, q\_144d, q\_144e
- No added in 16 questions: *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), q\_19, q\_20, q\_21, q\_30, q\_31, ...q\_40, q\_41, q\_63
- No removed in 14 questions: q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, q\_129, ...q\_136, q\_137, q\_138
- 1 added in *Father's birth order* (q\_108a), *Siblings' birth order* (q\_110a1), q\_38.1a, q\_38.1b, q\_38.2a and q\_38.2b
- factor variable q\_133, q\_134 and q\_99.c1 doesn't have defined level *Yes*

- 2 added in *Mother's birth order* (q\_107a) and *Father's number of siblings* (q\_108b)
- cannot convert value **Urban area** to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- **Antalya** added in *Medical facility* (facility\_id)
- **Hilmi Uysal** added in *Physician recording the data* (person\_id)
- 2016-03-11 replaces value 2086-03-13 in *Date of consultation* (q\_4)
- 1979-01-18 replaces value 2049-01-19 in *Date of birth* (q\_5)
- factor variable *Ethnicity* (q\_7) doesn't have defined level **Caucassian**
- **None** added in *Which cognitive symptoms at onset* (q\_22)
- **Right** added in *Handedness* (q\_23)
- **Positive** added in q\_43
- 2 replaces value **NA** in *Year of initiation of smoking* (q\_88b)
- *Year of interruption of smoking* (q\_88d) doesn't allow for tagged **NA 2**
- 0 added in *Mean number of packs/day* (q\_88e)
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- 9 added in *Mother's number of siblings* (q\_107b)
- 4 added in *Number of siblings* (q\_110a2)
- cannot convert value **Yes** to number in q\_121a
- **"Tourism"** removed in *Main Occupation* (q\_139)
- **"No"** removed in *Second Occupation* (q\_141)
- **"ANTC"** removed in *centr\_id*
- 47 replaces value 581 in *x*

## Changes to the patient ANTC0012

- **NA** added in 152 questions: *Regular specific diet - No* (q\_114a), *Regular specific diet - Mediterranean* (q\_114b), *Regular specific diet - Vegetarian* (q\_114c), *Regular specific diet - Vegan* (q\_114d), *Regular specific diet - Gluten-free* (q\_114e), *Regular specific diet - High protein* (q\_114f), *Regular specific diet - Low carbohydrate* (q\_114g), ... *Metastasis - Colon* (q\_85b\_7), *Metastasis - Rectum* (q\_85b\_8), *Metastasis - other Abdominal* (q\_85b\_9)
- cannot convert value **No** to number in 22 questions: q\_117a, q\_117b, q\_117c, q\_118a, q\_118b, q\_118c, q\_119a, ... q\_144c, q\_144d, q\_144e
- **No** removed in 19 questions: q\_110d, q\_123, q\_124, q\_125, q\_126, q\_127, q\_128, ... q\_145, q\_146, q\_147
- **No** added in 16 questions: *Head/Neck trauma in the last 5 years* (q\_115), *Head/Neck trauma > 5 years* (q\_116), q\_19, q\_20, q\_21, q\_30, q\_31, ... q\_40, q\_41, q\_63
- 1 added in q\_38.1a, q\_38.1b, q\_38.2a and q\_38.2b
- factor variable q\_133 and q\_99.c1 doesn't have defined level **Yes**
- cannot convert value **Yes** to number in q\_120b and q\_120c
- **"Technician"** removed in *Main Occupation* (q\_139) and *Second Occupation* (q\_141)

- Large town- > 100 000 removed in *Place of living* (q\_143) and *Place of living* (q\_144)
- cannot convert value Urban area to number in *Lives in Rural Area/Urban* (q\_143a) and *Lives in Rural Area/Urban* (q\_144a)
- Antalya added in *Medical facility* (facility\_id)
- Hilmi Uysal added in *Physician recording the data* (person\_id)
- 2017-01-12 replaces value 2087-01-14 in *Date of consultation* (q\_4)
- 1967-01-01 replaces value 2037-01-02 in *Date of birth* (q\_5)
- factor variable *Ethnicity* (q\_7) doesn't have defined level *Caucassian*
- None added in *Which cognitive symptoms at onset* (q\_22)
- Right added in *Handedness* (q\_23)
- Positive added in q\_43
- Type II replaces value Type I in q\_74
- *Year of initiation of smoking* (q\_88b) doesn't allow for tagged NA 2
- 0 added in *Mean number of packs/day* (q\_88e)
- 2018-02-20 added in *Date of initiation of Riluzole* (q\_91b)
- "ANTC" removed in centr\_id
- 48 replaces value 582 in x

## Changes to data structure and layout when transforming *df1* into *df2*

The paragraph below shows differences in data layout between the datasets

### Changes to the question property Variable name

- "" replaces value "Place of living" for q\_143 and q\_144
- "" replaces value "Lives in Rural Area/Urban" for q\_143a and q\_144a
- "" replaces value "Medical facility" for facility\_id
- "" replaces value "Physician recording the data" for person\_id
- "Familial history of ALS" replaces value "How many family members 1 had a history of ALS" for q\_100a\_2
- "Familial history of ALS" replaces value "How many family members 2 had a history of ALS" for q\_100b\_2
- "Familial history of ALS" replaces value "How many family members 3 had a history of ALS" for q\_100c\_2
- "Familial history of FTD" replaces value "How many family members 1 had a history of FTD" for q\_101a\_2
- "Familial history of FTD" replaces value "How many family members 2 had a history of FTD" for q\_101b\_2
- "Familial history of FTD" replaces value "How many family members 3 had a history of FTD" for q\_101c\_2

- "Familial history of Alzheimer disease" replaces value "How many family members 1 had a history of Alzheimer disease" for q\_102a\_2
- "Familial history of Alzheimer disease" replaces value "How many family members 2 had a history of Alzheimer disease" for q\_102b\_2
- "Familial history of Alzheimer disease" replaces value "How many family members 3 had a history of Alzheimer disease" for q\_102c\_2
- "Familial history of Parkinson disease" replaces value "How many family members 1 had a history of Parkinson disease" for q\_103a\_2
- "Family history of multiple sclerosis" replaces value "How many family members 1 had a history of multiple sclerosis" for q\_104a\_2
- "Family history of multiple sclerosis" replaces value "How many family members 2 had a history of multiple sclerosis" for q\_104b\_2
- "Parents' and siblings' causes of death" replaces value "Age of family member 1 at the moment of death" for q\_106\_1d
- "Parents' and siblings' causes of death" replaces value "Age of family member 2 at the moment of death" for q\_106\_2d
- "Parents' and siblings' causes of death" replaces value "Age of family member 3 at the moment of death" for q\_106\_3d
- "Parents' and siblings' causes of death" replaces value "Age of family member 4 at the moment of death" for q\_106\_4d
- "Mother's number of siblings and birth order" replaces value "Mother's birth order" for q\_107a
- "Mother's number of siblings and birth order" replaces value "Mother's number of siblings" for q\_107b
- "Father's number of siblings and birth order" replaces value "Father's birth order" for q\_108a
- "Father's number of siblings and birth order" replaces value "Father's number of siblings" for q\_108b
- "" replaces value "Father's Place of birth" for q\_10a
- "" replaces value "Father's Place of birth characteristics" for q\_10b
- "" replaces value "Date of 1st Symptoms" for q\_11
- "Number of siblings and birth order" replaces value "Siblings' birth order" for q\_110a1
- "Number of siblings and birth order" replaces value "Number of siblings" for q\_110a2
- "Moderate aerobic activity (such as fast walking, swimming) >150 min/week" replaces value "How long moderate sport activity 1" for q\_112a\_1c
- "Moderate aerobic activity (such as fast walking, swimming)

- >150 min/week" replaces value "How long moderate sport activity 2" for q\_112a\_2c
- "Moderate aerobic activity (such as fast walking, swimming) >150 min/week" replaces value "How long moderate sport activity 3" for q\_112a\_3c
- "Moderate aerobic activity (such as fast walking, swimming) >150 min/week" replaces value "How long moderate sport activity 4" for q\_112a\_4c
- "Vigorous aerobic activity (such as running or aerobic dancing) >75 min/week" replaces value "How long vigorous sport activity 1" for q\_112b\_1c
- "Vigorous aerobic activity (such as running or aerobic dancing) >75 min/week" replaces value "How long vigorous sport activity 2" for q\_112b\_2c
- "Vigorous aerobic activity (such as running or aerobic dancing) >75 min/week" replaces value "How long vigorous sport activity 3" for q\_112b\_3c
- "Mild physical exercise <75 min/week, >1 year" replaces value "How long mild sport activity 1" for q\_113\_1c
- "Mild physical exercise <75 min/week, >1 year" replaces value "How long mild sport activity 2" for q\_113\_2c
- "" replaces value "Regular specific diet - No" for q\_114a
- "" replaces value "Regular specific diet - Mediterranean" for q\_114b
- "" replaces value "Regular specific diet - Vegetarian" for q\_114c
- "" replaces value "Regular specific diet - Vegan" for q\_114d
- "" replaces value "Regular specific diet - Gluten-free" for q\_114e
- "" replaces value "Regular specific diet - High protein" for q\_114f
- "" replaces value "Regular specific diet - Low carbohydrate" for q\_114g
- "" replaces value "Regular specific diet - Paleo (High-protein, high-fat, low-carbohydrate)" for q\_114h
- "" replaces value "Date of 1st Medical Consultation" for q\_12
- "" replaces value "Date of Diagnosis" for q\_13
- "" replaces value "Date of Invasive ventilation" for q\_14
- "" replaces value "Date of Death" for q\_15
- "Time gap between first-second specialist (months)" replaces value "Time gap between first-second specialist" for q\_151
- "Order of specialists that observed the patient" replaces value "Order of specialist 1 that observed the patient" for q\_154a\_1
- "Order of specialists that observed the patient" replaces value "Order of specialist 2 that observed the patient" for q\_154a\_2
- "Order of specialists that observed the patient" replaces value "Order of specialist 3 that observed the patient" for q\_154a\_3
- "Order of specialists that observed the patient" replaces value "Order of specialist 4 that observed the patient" for q\_154a\_4

- "Order of specialists that observed the patient" replaces value "Order of specialist 5 that observed the patient" for q\_154a\_5
- "Order of specialists that observed the patient" replaces value "Order of specialist 6 that observed the patient" for q\_154a\_6
- "Order of specialists that observed the patient" replaces value "Order of specialist 7 that observed the patient" for q\_154a\_7
- "Order of specialists that observed the patient" replaces value "Other type of specialist 7 that observed the patient" for q\_154c\_7
- "" replaces value "Did specialist 1 made diagnosis" for q\_154d\_1
- "" replaces value "Did specialist 2 made diagnosis" for q\_154d\_2
- "" replaces value "Did specialist 3 made diagnosis" for q\_154d\_3
- "" replaces value "Did specialist 4 made diagnosis" for q\_154d\_4
- "" replaces value "Did specialist 5 made diagnosis" for q\_154d\_5
- "" replaces value "Did specialist 6 made diagnosis" for q\_154d\_6
- "" replaces value "Did specialist 7 made diagnosis" for q\_154d\_7
- "Time gap between first medical observation and the specialist who made the diagnosis (months)" replaces value "Time gap between first medical observation and diagnosis" for q\_155
- "Generalized onset" replaces value "" for q\_16g
- "" replaces value "UMN vs LMN manifestation at onset" for q\_17
- "" replaces value "Limb onset" for q\_18a
- "" replaces value "Predominant side" for q\_18b
- "" replaces value "Which cognitive symptoms at onset" for q\_22
- "" replaces value "Handedness" for q\_23
- "Bulbar region" replaces value "" for q\_24
- "Upper Limbs" replaces value "" for q\_26
- "Lower Limbs" replaces value "" for q\_28
- "Axial muscles" replaces value "" for q\_30a
- "" replaces value "Alternative diagnosis" for q\_36b
- "" replaces value "Sensory changes" for q\_39
- "" replaces value "Date of consultation" for q\_4
- "Postural instability - NURT" replaces value "" for q\_42
- "" replaces value "Cognition - Qualitative evaluation" for q\_44
- "Cognition - ECAS observed value (normal range)" replaces value "Cognition - ECAS value (or NF, NA, NR)" for q\_45a
- "Cognition - ECAS observed value (normal range)" replaces value "Cognition - ECAS lower range" for q\_45b
- "Cognition - ECAS observed value (normal range)" replaces value "Cognition - ECAS upper range" for q\_45c
- "" replaces value "Depression - Qualitative evaluation" for q\_46
- "Depression - ALS depression inventory" replaces value "ALS depression inventory value (or NF, NA, NR)" for q\_47a
- "Depression - ALS depression inventory" replaces value "ALS depression inventory upper range" for q\_47b
- "Depression - ALS depression inventory" replaces value "ALS

- depression inventory lower range" for q\_47c
- "Timing of transition from region 1 to 2 (months)" replaces value "Timing of transition from region 1 to 2" for q\_49c
- "" replaces value "Date of birth" for q\_5
- "Timing of transition from region 2 to 3 (months)" replaces value "Timing of transition from region 2 to 3" for q\_50b
- "" replaces value "ALSFRS(1) Acquisition date" for q\_51\_1.date
- "ALSFRS(1) Score" replaces value "ALSFRS-R total" for q\_51\_1.score
- "" replaces value "ALSFRS(2) Acquisition date" for q\_51\_2.date
- "ALSFRS-R history" replaces value "ALSFRS-R take 2 total" for q\_51\_2.score
- "" replaces value "Gender" for q\_6
- "" replaces value "Brain MRI - Normal" for q\_64\_1
- "" replaces value "Brain MRI - Tumor" for q\_64\_2
- "" replaces value "Brain MRI - Stroke" for q\_64\_3
- "" replaces value "Brain MRI - Multiple Sclerosis" for q\_64\_4
- "" replaces value "Brain MRI - Trauma" for q\_64\_5
- "" replaces value "Brain MRI - Hypoxia" for q\_64\_6
- "" replaces value "Brain MRI - NA" for q\_64\_7
- "" replaces value "Spinal cord MRI Cervical - Normal" for q\_65a\_1
- "" replaces value "Spinal cord MRI Cervical - Tumor" for q\_65a\_2
- "" replaces value "Spinal cord MRI Cervical - Stenosis" for q\_65a\_3
- "" replaces value "Spinal cord MRI Cervical - Myelitis" for q\_65a\_4
- "" replaces value "Spinal cord MRI Cervical - Trauma" for q\_65a\_5
- "" replaces value "Spinal cord MRI Cervical - Syringomyelia" for q\_65a\_6
- "" replaces value "Spinal cord MRI Cervical - Other" for q\_65a\_7
- "" replaces value "Spinal cord MRI Cervical - NA" for q\_65a\_8
- "" replaces value "Spinal cord MRI Thoracic - Normal" for q\_65b\_1
- "" replaces value "Spinal cord MRI Thoracic - Tumor" for q\_65b\_2
- "" replaces value "Spinal cord MRI Thoracic - Stenosis" for q\_65b\_3
- "" replaces value "Spinal cord MRI Thoracic - Myelitis" for q\_65b\_4
- "" replaces value "Spinal cord MRI Thoracic - Trauma" for q\_65b\_5
- "" replaces value "Spinal cord MRI Thoracic - Syringomyelia" for q\_65b\_6
- "" replaces value "Spinal cord MRI Thoracic - Other" for q\_65b\_7
- "" replaces value "Spinal cord MRI Thoracic - NA" for q\_65b\_8
- "" replaces value "Spinal cord MRI Lumbo-sacral - Normal" for q\_65c\_1
- "" replaces value "Spinal cord MRI Lumbo-sacral - Tumor" for q\_65c\_2
- "" replaces value "Spinal cord MRI Lumbo-sacral - Stenosis" for

- q\_65c\_3
- "" replaces value "Spinal cord MRI Lumbo-sacral - Myelitis" for q\_65c\_4
- "" replaces value "Spinal cord MRI Lumbo-sacral - Trauma" for q\_65c\_5
- "" replaces value "Spinal cord MRI Lumbo-sacral - Syringomyelia" for q\_65c\_6
- "" replaces value "Spinal cord MRI Lumbo-sacral - Other" for q\_65c\_7
- "" replaces value "Spinal cord MRI Lumbo-sacral - NA" for q\_65c\_8
- "" replaces value "Ethnicity" for q\_7
- "Diabetes - type I / II" replaces value "" for q\_74
- "" replaces value "Primary cancer - Brain" for q\_85a\_1
- "" replaces value "Primary cancer - Prostate" for q\_85a\_10
- "" replaces value "Primary cancer - Uterus" for q\_85a\_11
- "" replaces value "Primary cancer - other Plevic" for q\_85a\_12
- "" replaces value "Primary cancer - Spine" for q\_85a\_13
- "" replaces value "Primary cancer - UL bone & sarcomas" for q\_85a\_14
- "" replaces value "Primary cancer - LL bone & sarcomas" for q\_85a\_15
- "" replaces value "Primary cancer - Skin" for q\_85a\_16
- "" replaces value "Primary cancer - Leukemia" for q\_85a\_17
- "" replaces value "Primary cancer - Lymphoma" for q\_85a\_18
- "" replaces value "Primary cancer - other Blood" for q\_85a\_19
- "" replaces value "Primary cancer - Neck" for q\_85a\_2
- "" replaces value "Primary cancer - Breast" for q\_85a\_3
- "" replaces value "Primary cancer - Lung" for q\_85a\_4
- "" replaces value "Primary cancer - other Thoracic" for q\_85a\_5
- "" replaces value "Primary cancer - Gastric" for q\_85a\_6
- "" replaces value "Primary cancer - Colon" for q\_85a\_7
- "" replaces value "Primary cancer - Rectum" for q\_85a\_8
- "" replaces value "Primary cancer - other Abdominal" for q\_85a\_9
- "" replaces value "Metastasis - Brain" for q\_85b\_1
- "" replaces value "Metastasis - Prostate" for q\_85b\_10
- "" replaces value "Metastasis - Uterus" for q\_85b\_11
- "" replaces value "Metastasis - other Plevic" for q\_85b\_12
- "" replaces value "Metastasis - Spine" for q\_85b\_13
- "" replaces value "Metastasis - UL bone & sarcomas" for q\_85b\_14
- "" replaces value "Metastasis - LL bone & sarcomas" for q\_85b\_15
- "" replaces value "Metastasis - Skin" for q\_85b\_16
- "" replaces value "Metastasis - Leukemia" for q\_85b\_17
- "" replaces value "Metastasis - Lymphoma" for q\_85b\_18
- "" replaces value "Metastasis - other Blood" for q\_85b\_19
- "" replaces value "Metastasis - Neck" for q\_85b\_2
- "" replaces value "Metastasis - Breast" for q\_85b\_3



- "" replaces value "Metastasis - Lung" for q\_85b\_4
- "" replaces value "Metastasis - other Thoracic" for q\_85b\_5
- "" replaces value "Metastasis - Gastric" for q\_85b\_6
- "" replaces value "Metastasis - Colon" for q\_85b\_7
- "" replaces value "Metastasis - Rectum" for q\_85b\_8
- "" replaces value "Metastasis - other Abdominal" for q\_85b\_9
- "Date of initiation of smoking (year)" replaces value "Year of initiation of smoking" for q\_88b
- "Date of interruption of smoking (year)" replaces value "Year of interruption of smoking" for q\_88d
- "" replaces value "Place of birth" for q\_8a
- "" replaces value "Place of birth characteristics" for q\_8b
- "" replaces value "Date of initiation of Riluzole" for q\_91b
- "" replaces value "Abnormal C9orf72 repeat-expansion" for q\_98\_1
- "" replaces value "TBK1 mutation" for q\_98\_2a
- "" replaces value "Other gene 1" for q\_99.a1
- "" replaces value "Other gene 2" for q\_99.a2
- "Was the patient included in other genomic studies" replaces value "" for q\_99.c1
- "" replaces value "Mother's Place of birth" for q\_9a
- "" replaces value "Mother's Place of birth characteristics" for q\_9b

## Changes to the question property Variable labels dictionary

- "" replaces value "1="No";2="Yes"" for 155 questions: q\_114a, q\_114b, q\_114c, q\_114d, q\_114e, q\_114f, q\_114g, ...q\_85b\_7, q\_85b\_8, q\_85b\_9
- "" replaces value "NA(c)="NR";NA(a)="NA";NA(b)="NF"" for q\_88b, q\_88d and q\_88e
- "" replaces value "1="Rural area";2="Urban area"" for q\_143a and q\_144a
- "" replaces value "NA(a)="NA";NA(d)="unknown"" for q\_49c and q\_50b
- "" replaces value "0="Loss of useful speech";1="Speech combined with nonvocal communication";2="Intelligible with repeating";3="Detectable speech disturbances";4="Normal speech processes"" for q\_51\_1.1 and q\_51\_2.1
- "" replaces value "0="Significant difficulty, considering using mechanical respiratory support";1="Occurs at rest Shortness of breath at rest, difficulty breathing when either sitting or lying";2="Occurs with >= 1 of the following: eating, bathing, dressing (ADL)";3="Occurs when walking";4="None"" for q\_51\_1.10 and q\_51\_2.10
- "" replaces value "0="Unable to sleep";1="Can only sleep sitting up";2="Needs extra pillows in order to sleep (>2)";3="Some

- difficulty sleeping at night due to shortness of breath  
(does not routinely use more than two pillows)";4="None"  
for q\_51\_1.11 and q\_51\_2.11
- "" replaces value "0="Invasive mechanical ventilation by intubation or tracheostomy";1="Continuous use of BiPAP during the night and day";2="Continuous use of BiPAP during the night";3="Intermittent use of BiPAP";4="None"" for q\_51\_1.12 and q\_51\_2.12
  - "" replaces value "0="Marked drooling; requires constant tissue or handkerchief";1="Marked excess of saliva with some drooling";2="Moderately excessive saliva; may have minimal drooling";3="Slight but definite excess of saliva in mouth; may have nighttime drooling";4="Normal"" for q\_51\_1.2 and q\_51\_2.2
  - "" replaces value "0="NPO (exclus. parenteral or enteral feeding)";1="Needs supplemental tube feeding";2="Dietary consistency changes";3="Early eating problems - occasional choking";4="Normal eating habits"" for q\_51\_1.3 and q\_51\_2.3
  - "" replaces value "0="Unable to grip pen";1="Able to grip pen but unable to write";2="Not all words are legible";3="Slow or sloppy; all words are legible";4="Normal"" for q\_51\_1.4 and q\_51\_2.4
  - "" replaces value "0="Needs to be fed";1="Food must be cut by someone, but can still feed slowly";2="Can cut most foods, although clumsy and slow; some help needed";3="Somewhat slow and clumsy, but no help needed";4="Normal"" for q\_51\_1.5 and q\_51\_2.5
  - "" replaces value "0="Total dependence";1="Needs attendant for self-care";2="Intermittent assistance or substitute methods";3="Independent and complete self-care with effort of decreased efficiency";4="Normal function"" for q\_51\_1.6 and q\_51\_2.6
  - "" replaces value "0="Helpless";1="Can initiate, but not turn or adjust sheets alone";2="Can turn alone or adjust sheets, but with great difficulty";3="Somewhat slow and clumsy, but no help needed";4="Normal"" for q\_51\_1.7 and q\_51\_2.7
  - "" replaces value "0="No purposeful leg movement";1="Nonambulatory functional movement";2="Walks with assistance";3="Early ambulation difficulties";4="Normal"" for q\_51\_1.8 and q\_51\_2.8
  - "" replaces value "0="Cannot do";1="Needs assistance";2="Mild unsteadiness or fatigue";3="Slow";4="Normal"" for q\_51\_1.9 and q\_51\_2.9
  - "1="Antalya";2="Hannover";3="Jena";4="Lisbon";5="Pisa";6="Warsaw"" replaces value "" for facility\_id
  - "1="Annalisa Logerfo";2="B Stubbendorf";3="Hilmi Uysal";4="K Szacka";5="Mamede de Carvalho";6="Susanne Petri-Mals"" replaces

- value "" for person\_id
- "" replaces value "NA(a)='NA';NA(b)='NF';NA(c)='NR'" for q\_151
- "" replaces value "NA(a)='NA';NA(b)='NF'" for q\_155
- "1='No answer required for this field'" replaces value "1='No answer required for this field';2='NA'" for q\_156
- "" replaces value "1='Positive';2='Negative';NA(b)='Positive';NA(b)='Negative'" for q\_42
- "1='No';2='Head';3='Neck';4='Head and neck'" replaces value "1='No';2='Head';3='Neck';4='Head and neck';5='NA';6='Yes'" for q\_87b

## Changes to the question property class

- integer** replaces value **nominal** for 157 questions: q\_114a, q\_114b, q\_114c, q\_114d, q\_114e, q\_114f, q\_114g, ...q\_85b\_7, q\_85b\_8, q\_85b\_9
- integer** added for 45 questions: q\_100a\_2, q\_100b\_2, q\_100c\_2, q\_100d\_2, q\_101a\_2, q\_101b\_2, q\_101c\_2, ...q\_47c, q\_51\_2.score, x
- integer** replaces value **labelled** for 24 questions: q\_51\_1.1, q\_51\_1.10, q\_51\_1.11, q\_51\_1.12, q\_51\_1.2, q\_51\_1.3, q\_51\_1.4, ...q\_51\_2.7, q\_51\_2.8, q\_51\_2.9
- integer** replaces value **real number** for 17 questions: q\_107a, q\_107b, q\_108a, q\_108b, q\_110a1, q\_110a2, q\_112a\_1c, ...q\_88b, q\_88d, q\_88e
- nominal** replaces value **text** for facility\_id and person\_id
- integer** replaces value **text** for q\_154c\_7
- real number** added for q\_51\_1.score

## Other items

- NA removed in Theoretical min for q\_4 and q\_5
- NA added in Theoretical min for q\_51\_1.score
- "F" added in measure\_type for q\_16g, q\_24, q\_26, q\_28, q\_30a, q\_74 and q\_99.c1
- "I" added in measure\_type for q\_51\_1.score
- FALSE replaces value TRUE in Force only values that are labelled for 168 questions: q\_11, q\_114a, q\_114b, q\_114c, q\_114d, q\_114e, q\_114f, ...q\_85b\_7, q\_85b\_8, q\_85b\_9
- TRUE replaces value FALSE in Force only values that are labelled for facility\_id, person\_id and q\_51\_1.score
- "FALSE" added in Force only integral values for q\_74
- NA removed in Theoretical max for q\_4 and q\_5

- "FALSE" replaces value "1" in Force only non-missing values for facility\_id, person\_id, q\_11, q\_13, q\_4, q\_5, q\_6 and q\_7
- 0 removed in warnings\_context for 14 questions: facility\_id, person\_id, q\_107a, q\_107b, q\_108a, q\_108b, q\_110a1, ... q\_113\_1c, q\_151, q\_155