CHRIS Study

Interview – Neurology

Version 1.1

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Authors: LB, MG

1. Introduction

This module stores information related to the neurological diseases of the participants, that was collected at the interview.

Participants book a morning appointment at the CHRIS study center, ranging from 7.45 to 8.45 a.m. Each study participant is assigned a workflow at the reception. If there are ten study participants (maximum capacity), there are ten different workflows, marked with the letters from "A" to "K". The current workflow is as follows: A-B-C-D-E-F-G-H-I-K. All the workflows can be found in the documentation of CHRIS Baseline/General information/Administrative data, in the file named "Workflows at baseline assessment". The interview occurs always after the spiralography and the blood drawing, for most as the last session, after the ECG assessment and the self-administered questionnaire (workflows B, C, E, F, H, I, L). For the remainder, the interview occurs after breakfast and just before the self-administered questionnaire (workflows A and G) or in between the blood drawing and the anthropometry (workflow D).

The questionnaire was developed by researchers of the IfB, with the aim of assessing the most frequent neurological diseases.

The interview full text and its corresponding answer lists are available at CHRIS Baseline/Interview.

2. History version changes

Version 1 of this interview module was in use between August 24th,2011 and November 2nd, 2012; Version 2 was then in use since November 5th, 2012.

Version 1 to Version 2

variables dropped: x0ne01, x0ne01b, x0ne01c, x0ne01d, x0ne04, x0ne04b, x0ne04c, x0ne05, x0ne05b, x0ne05c, x0ne05d, x0ne05e, x0ne07c, x0ne07d, x0ne07e, x0ne11, x0ne11b, x0ne11c, x0ne11d, x0ne12, x0ne12a, x0ne12c, x0ne12d, x0ne13, x0ne13a, x0ne13c, x0ne13d, x0ne14a, x0ne14b, x0ne14c, x0ne14d, x0ne20, x0ne20a, x0ne20c, x0ne20d

variables added: x0ne09, x0ne09b, x0ne10, x0ne10b, x0ne21, x0ne21a, x0ne21c, x0ne21d, x0ne21e, x0ne22, x0ne22a, x0ne22c, x0ne22d, x0ne22e

question rephrased: x0ne06 (de), x0ne07 (de, it)

other: TIA questions (x0st20, x0st20b, x0st20c) were moved to the stroke module.

The cleaning process added the variables x0ne03a1, x0ne03a2, x0ne03a3, x0ne03a4, x0ne03a5, and x0ne03a6.

3. Data cleaning

1. The main CHRIS dataset was loaded.
2. The variable on diagnosis of either epilepsy or febrile seizures, x0ne01, had it observations transformed into:

a) "Not in use" (-98) if the questionnaire version was not the first (x0never>1),
b) "Unexpected missing" (-89) if they were missing,
c) "Don't know" (-88) if the option "I do not know" was chosen.

3. The variable on the age at the diagnosis of either epilepsy or febrile seizures, x0ne01b, had its observations transformed into:
   a) "Not in use" (-98) if the questionnaire version was not the first (x0never>1),
   b) "Missing by design" (-99) if they were missing and nor epilepsy nor febrile seizure was ever diagnosed (x0ne01="No", "Don't know" or "Missing by design"),
   c) "Unexpected missing" (-89) if they were still missing,
   d) "Don't know" (-88) if the reported age at diagnosis was 99.

4. The variables on the presence in the last 12 months and on treatment of either epilepsy or febrile seizures, x0ne01c and x0ne01d, had their observations transformed into:
   a) "Not in use" (-98) if the questionnaire version was not the first (x0never>1),
   b) "Missing by design" (-99) if they were missing and nor epilepsy nor febrile seizure was ever diagnosed (x0ne01="No", "Don't know" or "Missing by design"),
   c) "Unexpected missing" (-89) if they were still missing,
   d) "Don't know" (-88) if the option "I do not know" was chosen.

5. The variables on diagnosis of epilepsy diagnosis of the second questionnaire version, x0ne09 and x0ne10, had their observations transformed into:
   a) "Not in use" (-98) if the questionnaire version was the first (x0never=1),
   b) "Unexpected missing" (-89) if they were missing,
   c) "Don't know" (-88) if the option "I do not know" was chosen.

6. The variables on the age at the diagnosis of epilepsy and of febrile seizures, x0ne09b and x0ne10b, had their observations transformed into:
   a) "Not in use" (-98) if the questionnaire version was the first (x0never=1),
   b) "Missing by design" (-99) if they were missing and that disorder was never diagnosed (e.g., for x0ne09b, x0ne09="No", "Don't know" or "Missing by design"),
   c) "Unexpected missing" (-89) if they were still missing,
   d) "Don't know" (-88) if the reported age at diagnosis was 99.

7. The variables on presence of uncontrollable tremor, forgetfulness, diagnosis of multiple sclerosis, and paresthesia in the hand, x0ne02, x0ne06, x0ne07, x0ne08, had their observations transformed into:
   a) "Unexpected missing" (-89) if they were missing,
   b) "Don't know" (-88) if the option "I do not know" was chosen.

8. The variables on the diagnosis of uncontrollable tremor and its occurrence at rest and while moving, x0ne02a, x0ne03b, x0ne03c, had their observations transformed into:
   a) "Missing by design" (-99) if they were missing and no uncontrollable tremor was present (x0ne02="No", "Don't know" or "Missing by design"),
   b) "Unexpected missing" (-89) if they were still missing,
   c) "Don't know" (-88) if the option "I do not know" was chosen.

9. The variables on the age at the diagnosis of uncontrollable tremor and its treatment, x0ne02c and x0ne02d, had their observations transformed into:
   a) "Missing by design" (-99) if they were missing and no uncontrollable tremor was ever diagnosed (x0ne02a="No", "Don't know" or "Missing by design"),

b) "Unexpected missing" (-89) if they were still missing,

c) "Don't know" (-88) if the reported age at diagnosis was 99 or the option "Don't know" was chosen.

10. The variables on the presence in the last 12 months and on treatment of uncontrollable tremor, x0ne02c and x0ne02d, had its observations transformed into:

   a) "Not in use" (-98) if the questionnaire version was not the first (x0never>1),

   b) "Missing by design" (-99) if they were missing and nor epilepsy nor febrile seizure was ever diagnosed (x0ne01="No", "Don't know" or "Missing by design"),

   c) "Unexpected missing" (-89) if they were still missing,

   d) "Don't know" (-88) if the option "I do not know" was chosen.

11. The variable on the tremor location, x0ne03a, was then categorized into more variables, one for each body part: arms, hands, fingers, legs, head, and trunk. For the variables referring to tremor in arms, hands, fingers, and legs, x0ne03a1, x0ne03a2, x0ne03a3, and x0ne03a4, had as categories "Yes, bilateral", "Yes, right side", "Yes, left side", "Yes, laterality unknown", and "No". The variables on tremor in the head and trunk, x0ne03a5 and x0ne03a6, had as categories "Yes" and "No". The use of the plural term for arm, hand, and leg (*Arme, Hände, Beine*), or the use of the expression "both sides" or both right and left, would lead to the classification as "Yes, bilateral". Instead, the use of terms "fingers" or "knees" without reference to the side, lead to the classification as "Yes, laterality unknown", given that fingers could be on the same hand and the term knee and knees are equivalent in German (*Knie*).

12. The variable on diagnosis of forgetfulness and orientation problems, x0ne06a, had its observations transformed into:

   a) "Missing by design" (-99) if they were missing and nor forgetfulness nor orientation problem was reported (x0ne06="No", "Don't know" or "Missing by design"),

   b) "Unexpected missing" (-89) if they were missing,

   c) "Don't know" (-88) if the option "I do not know" was chosen.

13. The variable on the age at the diagnosis and treatment of forgetfulness and orientation problems, x0ne06c and x0ne06d, had their observations transformed into:

   a) "Not in use" (-98) if the questionnaire version was not the first (x0never>1),

   b) "Missing by design" (-99) if they were missing and nor forgetfulness nor orientation problem was ever diagnosed (x0ne06a="No", "Don't know" or "Missing by design"),

   c) "Unexpected missing" (-89) if they were still missing,

   d) "Don't know" (-88) if the reported age at diagnosis was 99 or the option "I do not know" was chosen.

14. If an age at diagnosis or treatment of forgetfulness and orientation problems was provided in x0ne06c or x0ne06d, the answer in the variable on diagnosis of forgetfulness was changed from "Unexpected missing" to "Yes".

15. The variable on age at diagnosis of multiple sclerosis, x0ne07b, had it observations transformed into:

   a) "Missing by design" (-99) if they were missing and multiple sclerosis was not diagnosed (x0ne07="No", "Don't know" or "Missing by design"),

   b) "Unexpected missing" (-89) if they were still missing,

   c) "Don't know" (-88) if the reported age at diagnosis was 99.

16. The variable on the presence, treatment, and disease course of multiple sclerosis, x0ne07c, x0ne07d, x0ne07e, had their observations transformed into:
    a) "Not in use" (-98) if the questionnaire version was not the first (x0never>1),
    b) "Missing by design" (-99) if they were missing and multiple sclerosis was not diagnosed (x0ne07="No", "Don't know" or "Missing by design"),
    c) "Unexpected missing" (-89) if they were still missing,
    d) "Don't know" (-88) if the option "I do not know" was chosen.

17. The variable on age at begin of paresthesia or (burning) pain in the hand, x0ne08b, had it observations transformed into:
    a) "Missing by design" (-99) if they were missing and paresthesia or (burning) pain in the hand was not reported (x0ne08="No", "Don't know" or "Missing by design"),
    b) "Unexpected missing" (-89) if they were still missing,
    c) "Don't know" (-88) if the reported age at diagnosis was 99.

18. The variables on diagnosis of Huntington disease, myoclonus/tic/dystonia, sleep disorders, circulatory disorders in the head/neck, vertigo, neurological symptoms, x0ne04, x0ne05, x0ne11, x0ne12, x0ne13, x0ne20, had their observations transformed into:
    a) "Not in use" (-98) if the questionnaire version was not the first (x0never>1),
    b) "Unexpected missing" (-89) if they were missing,
    c) "Don't know" (-88) if the option "I do not know" was chosen.

19. The variables on the age at the diagnosis and treatment of Huntington disease, x0ne04b and x0ne04c, had their observations transformed into:
    a) "Not in use" (-98) if the questionnaire version was not the first (x0never>1),
    b) "Missing by design" (-99) if they were missing and Huntington diseases was not diagnosed (x0ne04="No", "Don't know" or "Missing by design"),
    c) "Unexpected missing" (-89) if they were still missing,
    d) "Don't know" (-88) if the reported age at diagnosis was 99 or the option "I do not know" was chosen.

20. The variables on the age at the diagnosis, treatment, and type of myoclonus/tic/dystonia, x0ne05b, x0ne05c, and x0ne05d, had their observations transformed into:
    a) "Not in use" (-98) if the questionnaire version was not the first (x0never>1),
    b) "Missing by design" (-99) if they were missing and myoclonus/tic/dystonia was not diagnosed (x0ne05="No", "Don't know" or "Missing by design"),
    c) "Unexpected missing" (-89) if they were still missing,
    d) "Don't know" (-88) if the reported age at diagnosis was 99 or the option "I do not know" was chosen.

21. The variables on the age at the start, treatment frequency, and type of sleep disorders, x0ne11b, x0ne11c, and x0ne11d, had their observations transformed into:
    a) "Not in use" (-98) if the questionnaire version was not the first (x0never>1),
    b) "Missing by design" (-99) if they were missing and sleep disorders were not reported (x0ne11="No", "Don't know" or "Missing by design"),
    c) "Unexpected missing" (-89) if they were still missing,
    d) "Don't know" (-88) if the reported age at diagnosis was 99 or the option "I do not know" was chosen.

22. The variables on the diagnosis, age at diagnosis, and current treatment of circulatory disorders of the head/neck, x0ne12a, x0ne12c, and x0ne12d, had their observations transformed into:
    a) "Not in use" (-98) if the questionnaire version was not the first (x0never>1),
    b) "Missing by design" (-99) if they were missing and circulatory disorders of the head/neck were not reported (x0ne12="No", "Don't know" or "Missing by design"),
    c) "Unexpected missing" (-89) if they were still missing,
    d) "Don't know" (-88) if the reported age at diagnosis was 99 or the option "I do not know" was chosen.
23. The variables on the diagnosis and type of vertigo, x0ne13a, x0ne14a-x0ne14d, had their observations transformed into:
    a) "Not in use" (-98) if the questionnaire version was not the first (x0never>1),
    b) "Missing by design" (-99) if they were missing and vertigo was not reported (x0ne13="No", "Don't know" or "Missing by design"),
    c) "Unexpected missing" (-89) if they were still missing,
    d) "Don't know" (-88) if the reported age at diagnosis was 99 or the option "I do not know" was chosen.
24. The variables on the age at diagnosis and current treatment of vertigo, x0ne13c and x0ne13d, had their observations transformed into:
    a) "Not in use" (-98) if the questionnaire version was not the first (x0never>1),
    b) "Missing by design" (-99) if they were missing and vertigo was not diagnosed (x0ne13a="No", "Don't know" or "Missing by design"),
    c) "Unexpected missing" (-89) if they were still missing,
    d) "Don't know" (-88) if the reported age at diagnosis was 99 or the option "I do not know" was chosen.
25. The variable on diagnosis of any other neurological symptoms/disease in the first questionnaire version, x0ne20a, had its observations transformed into:
    a) "Not in use" (-98) if the questionnaire version was not the first (x0never>1),
    b) "Missing by design" (-99) if they were missing and no other neurological symptoms/disease was reported (x0ne20="No", "Don't know" or "Missing by design"),
    c) "Unexpected missing" (-89) if they were still missing,
    d) "Don't know" (-88) if the option "I do not know" was chosen.
26. The variables on the age at diagnosis and treatment of any other neurological symptoms/disease in the first questionnaire version, x0ne20c and x0ne20d, had their observations transformed into:
    a) "Not in use" (-98) if the questionnaire version was not the first (x0never>1),
    b) "Missing by design" (-99) if they were missing and no other neurological symptoms/disease was diagnosed (x0ne20a="No", "Don't know" or "Missing by design"),
    c) "Unexpected missing" (-89) if they were still missing,
    d) "Don't know" (-88) if the reported age at diagnosis was 99 or the option "I do not know" was chosen.
27. The variable on the presence of any other neurological symptoms/disease in the second questionnaire version, x0ne21, had its observations transformed into:
    a) "Not in use" (-98) if the questionnaire version was the first (x0never=1),

b) "Unexpected missing" (-89) if they were still missing,

c) "Don't know" (-88) if the option "I do not know" was chosen.

28. The variable on diagnosis of any other neurological symptoms/disease in the second questionnaire version, x0ne21a, had its observations transformed into:

    a) "Not in use" (-98) if the questionnaire version was the first (x0never=1),

    b) "Missing by design" (-99) if they were missing and no other neurological symptoms/disease was reported (x0ne21="No", "Don't know" or "Missing by design"),

    c) "Unexpected missing" (-89) if they were still missing,

    d) "Don't know" (-88) if the option "I do not know" was chosen.

29. The variables on age at diagnosis and treatment of any other neurological symptoms/disease in the second questionnaire version, x0ne21c and x0ne21d, had their observations transformed into:

    a) "Not in use" (-98) if the questionnaire version was the first (x0never=1),

    b) "Missing by design" (-99) if they were missing and no other neurological symptoms/disease was diagnosed (x0ne21a="No", "Don't know" or "Missing by design"),

    c) "Unexpected missing" (-89) if they were still missing,

    d) "Don't know" (-88) if the reported age at diagnosis was 99 or the option "I do not know" was chosen.

30. The variable on the presence of additional neurological symptoms/disease in the second questionnaire version, x0ne22, had its observations transformed into:

    a) "Not in use" (-98) if the questionnaire version was the first (x0never=1),

    b) "Missing by design" (-99) if no other neurological symptoms/disease was reported (x0ne21="No", "Don't know" or "Missing by design"),

    c) "Unexpected missing" (-89) if they were still missing,

    d) "Don't know" (-88) if the option "I do not know" was chosen.

31. The variables on the diagnosis, age at diagnosis, and treatment of additional neurological symptoms/disease in the second questionnaire version, x0ne22a-x0ne22d, had their observations transformed similarly to what was done for x0ne21a-x0ne21d.

32. The year variables x0ne01a, x0ne02b, x0ne04a, x0ne05a, x0ne06b, x0ne07a, x0ne08a, x0ne09a, x0ne10a, x0ne11a, x0ne12b, x0ne13b, x0ne20b, x0ne21b, and x0ne22b, were dropped in favor of the age variables x0ne01b, x0ne02c, x0ne04b, x0ne05b, x0ne06c, x0ne07b, x0ne08b, x0ne09b, x0ne10b, x0ne11b, x0ne12c, x0ne13c, x0ne20c, x0ne21c, and x0ne22c.

33. The variables specifying the additional neurological symptoms/diseases, x0ne21e and x0ne22e, were translated and categorized according to the symptoms when possible.

34. The variables storing the notes additional information on neurological symptoms, x0nen1, x0nen2, x0nen4, x0nen5, x0nen6, x0nen7, and x0nenote, were translated and categorized when possible.

35. The baseline dataset was saved.

4. Advices for the analysis

The content of the nurse's notes includes information on epilepsy, tremor, forgetfulness, multiple sclerosis, carpal tunnel syndrome as well as any other neurological disorders. Information on migraine

and Parkinson disease were instead collected with the interview modules Migraine and Parkinson, respectively (x0mg and x0pk modules).

The current medications can be looked at in the drugs module x0dd, where the participant let their current medication packages be scanned by the nurse at the study center. Specifically, the variable x0dd29 describes use of antineoplastic and immunomodulating agents, the variables x0dd38 and x0dd39 stand respectively for intake of psycholeptics and psychoanaleptics, whereas the variable x0dd43 describes current use of antivertigo drugs.

The variables on further, not previously mentioned, neurological disorders, x0ne21 and x0ne22, depend on the participant recalling such disorders and knowing their neurological nature. Indeed, many participants reported also psychological disorders in these questions.

Out of those reporting having uncontrollable tremor in x0ne02, only 23% reported to have actually been diagnosed with tremor in x0ne02a.

The variables on the occurrence and treatment of a specific neurological disease in the previous 12 months, x0ne01c, x0ne01d, x0ne04c, x0ne05c, x0ne05d, x0ne07c, and x0ne07d, should not be considered for analysis, given that they were available only for the first questionnaire version.

Finally, the analyst should always take into account that the operator in charge of carrying out the interview might have influenced how the participant reported their answers. The analyst should therefore adjust for the operator variable, x0_opintc, when possible.