

3. At what age were the symptoms the worst, and what were they?

.....
.....
.....
.....

4. For how long did this period last, and when did you feel the worst?

.....

5. Have you ever been free of symptoms? If yes, for how long did that period last?

.....
.....
.....

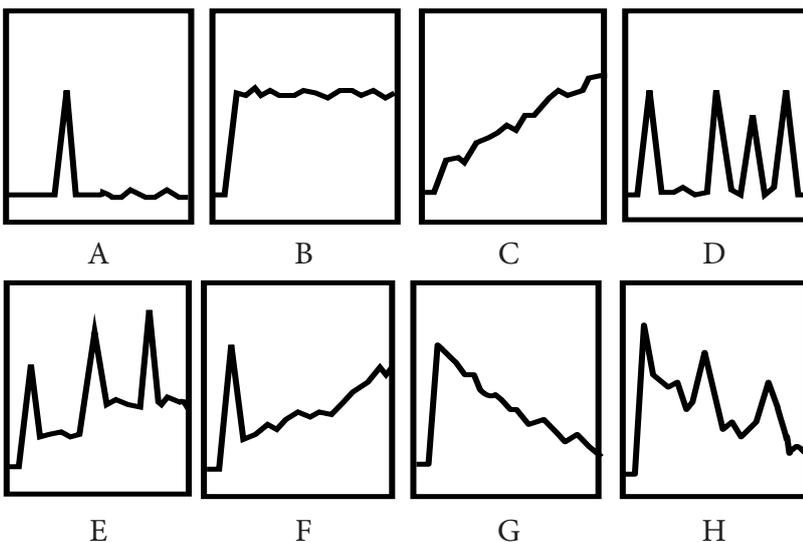
6. Were there any events that may be related to the emergence of your problems (e.g., vaccinations, travel, infection, personal loss, strong frightening experience or other)?

.....
.....
.....

Symptom duration plot

The figures below depict possible courses of symptoms and/or progression of the problem. Show them to the person who you are interviewing and ask him/her to choose the most appropriate figure to describe the course. The horizontal axis depicts time, and the vertical axis depicts symptom severity. Please provide information on treatments and, if possible, the year and month of changes in symptoms and treatments. Different figures can be selected for different types of problems. You may use a separate sheet of paper and assist the person in charting the symptoms.

Flares are defined as new or worsening symptoms that develop over the course of hours or days and last at least 24 hours. Other factors, particularly infections and fever, should be considered the cause of the deterioration. Relapses usually last one to several weeks, and the symptoms remit fully or partly. At least 30 days must pass between onset and relapse in order to distinguish them.



7. If there is a relapsing course, how many relapses of OCD/hoarding/tics/anorexia/restricted eating/ other severe symptoms with a sudden onset (< 3 days) have you experienced? N/A
8. Are relapses related to infections or fever? (circle as applicable) Yes No Don't know
9. Have you noticed whether you improve or deteriorate when you have a fever? (circle as applicable) Yes No Don't know
10. Are relapses related to other factors? Yes No Don't know
 Comment:.....
11. How old were you when you first sought help for your problems (e.g. for sleep disturbances, GLARE [difficult to comfort], eating problems, delayed psychomotor development, social problems, tics, or deviant language development)? years
- a. For which problems did you seek help?

- b. Do you still have these problems? Yes No Partly Don't know N/A

12. Are you worried about your physical health? Yes No Don't know
- a. If yes: What is your concern?

- b. When did you first become worried about your physical health?
 years of age (or what year?)
13. Are you worried about your mental health? Yes No Don't know
- a. If yes: What is your concern?

- b. When did you first become worried about your mental health?
 years of age (or what year?)
- c. When did you first become worried about the problems you present today?
 years of age (or what year?)
- d. Did you receive a diagnosis at the time? Yes No Don't know
- e. If yes, which diagnosis/es?

Question G in the self-assessment

14. Do you have a physical illness or a physical diagnosis? Yes No Don't know
- a. If yes, which one(s), and at what age were you diagnosed?
- years
15. Do you have a mental disorder or disability? Yes No Don't know
- a. If yes, which one(s), and at what age were you diagnosed?
- years
- years
- years
- years
- b. Do you have other problems that you presume should be diagnosed but where a formal diagnosis is lacking? Yes No Don't know
- c. If yes, which, and at approximately what age did these symptoms/problems emerge?
- years
- years
- years
- years

Questions H-P in the self-assessment

16. If you have received treatment earlier, please specify the treatment (psychological, pharmaceutical, ECT, or other treatment) psychological pharmaceutical ECT other no treatment
-
-
-
-
-
-
-
-
-
-
-
- a. If you had side-effects, what were they?
-
-
-
- b. If medical treatment is ongoing, which medication(s) (regardless of which) and what dosage(s)?
-
-
-
-

c. If psychological or other treatment is presently ongoing, what kind of intervention is it?

.....
.....

d. How was the effect of the treatment(s) you received (pharmaceutical/psychological/other; what kind)?

The effect of treatment was obvious some no difference worse
 transient permanent not sure

The effect of treatment was obvious some no difference worse
 transient permanent not sure

The effect of treatment was obvious some no difference worse
 transient permanent not sure

The effect of treatment was obvious some no difference worse
 transient permanent not sure

Comment:
.....

Question HH in the self-assessment

Go through the patient's/related person's responses in the self-report and specify endorsed symptoms – suggestions are shown below. Skip those questions that have been negated in the self-report (unless there is ambiguity in the patient's response or assuming the patient is dissimulating).

Circle specifications of present endorsed symptoms. To illustrate connections, draw lines between specifications of endorsed symptoms and comments and underline relevant comments. The same comments could apply to various specifications.

Points are given based on confirmed current symptoms during the *past 2 weeks*. At present there is no scientific evidence that a particular disorder exists based on the scores, rather they are intended to be used to follow progress.

<i>Specification of endorsed symptoms</i>	<i>Comments</i>
1. Obsessive/compulsive symptoms and hoarding <input type="checkbox"/> Absolutely = 2 <input type="checkbox"/> To some extent = 1 <input type="checkbox"/> No = 0 <input type="checkbox"/> Don't know = 1	
a. excessive hand washing/fear of dirt/fear of contracting a disease	– has attracted attention from others – more difficult to treat than expected
b. checking locks, checking doors, checking electrical appliances, checking that things have not been lost	– not determined whether it is OCD related – required psychiatric treatment
c. requirements for a certain order or symmetry, ordering or repeating certain actions to reach "just the right feeling", or requiring others to repeat certain actions	– relapse remitting course – chronic course – progressive course
d. hoarding	– associated with general deterioration
e. obsessions typical for OCD, such as fear of harming	

-
5. Irritability Absolutely = 2 To some extent = 1 No = 0 Don't know = 1
- a. sulks for prolonged periods of time about "nothing" – has attracted attention from others
 - b. has fits of rage – perceived as related to stress
 - c. irritable most of the time – relapse remitting course
 - d. intimidating – chronic course
 - progressive course
 - associated with general deterioration

-
6. Oppositional defiant behavior Absolutely = 2 To some extent = 1 No = 0 Don't know = 1
- a. often refuses to follow prompts – caused conflicts at home
 - b. often irritates others purposely – caused conflicts at school/work
 - c. often quick to fight back when somebody did something wrong – caused conflicts with friends/peers
 - d. easily loses temper – caused a virtually unbearable home situation
 - relapse remitting course
 - chronic course
 - progressive course
 - associated with general deterioration

-
7. Physically violent Absolutely = 2 To some extent = 1 No = 0 Don't know = 1
- a. has beaten others – family members or others have felt fear because of the outbreaks
 - b. has shoved others – fear that the patient will hurt someone
 - c. has smashed or destroyed things on purpose – not done with intent to harm but may result in harm
 - d. has hurt him-/herself – outbreaks have caused serious conflicts
 - has required police assistance or similar actions
 - has been prosecuted/convicted/sentenced for violent behavior
 - relapse remitting course
 - chronic course
 - progressive course
 - associated with general deterioration
-

-
8. Personality changes Absolutely = 2 To some extent = 1 No = 0 Don't know = 1
- a. some changes compared with before onset – has attracted attention from others
 - b. significantly altered (e.g., becomes intimidating) – scares family members
 - c. appears as a stranger – occurs in bouts
 - d. behaves as though obsessed, feels like a horror movie
 - relapse remitting course
 - chronic course
 - progressive course
 - associated with general deterioration

-
9. Abnormal psychomotor development Absolutely = 2 To some extent = 1 No = 0 Don't know = 1
- a. loss of theoretical knowledge – probably has an inborn intellectual disability
 - b. loss of practical abilities – probably has an acquired intellectual disability
 - c. loss of language skills – relapse remitting course
 - d. behaves much younger than chronological age – chronic course
 - e. baby-like behavior – progressive course
 - f. marginal intellectual disability (IQ 70–85) – associated with general deterioration
 - g. intellectual disability

-
10. Difficulties managing school or work Absolutely = 2 To some extent = 1 No = 0 Don't know = 1
- a. impaired concentration – has attracted attention from others
 - b. forgetful of what has been learned, impaired working memory – cannot attend class anymore or unable to continue working
 - c. has become worse at for example mathematics
 - attends special education
 - relapse remitting course
 - chronic course
 - progressive course
 - associated with general deterioration

-
14. Sense of being watched Absolutely = 2 To some extent = 1 No = 0 Don't know = 1
- | | |
|---------------------------------|---|
| a. suspicious of others | - has attracted attention from others |
| b. suspicious of family members | - requires psychiatric care |
| c. feels persecuted | - relapse remitting course |
| d. ideas of reference | - chronic course |
| e. paranoid delusions | - progressive course |
| | - associated with general deterioration |

-
15. Confused behavior or incoherent speech Absolutely = 2 To some extent = 1 No = 0 Don't know = 1
- | | |
|--|---|
| a. cannot participate in a coherent conversation | - has attracted attention from others |
| b. incoherent speech | - requires psychiatric care |
| c. mostly unresponsive | - relapse remitting course |
| d. unresponsive/mute | - chronic course |
| | - progressive course |
| | - associated with general deterioration |

-
16. Catatonia, mutism Absolutely = 2 To some extent = 1 No = 0 Don't know = 1
- | | |
|---|---|
| a. trapped in body movements | - has attracted attention from others |
| b. stands as a statue for lengths of time | - is associated with anxiety |
| c. speaks only with family members and not with others,
i.e., selective mutism | - relapse remitting course |
| | - chronic course |
| d. speaks to nobody (but has speech), i.e., mutism | - progressive course |
| | - associated with general deterioration |
-

17. Involuntary or unusual movements or noises

Absolutely = 2 To some extent = 1 No = 0 Don't know = 1

- a. simple motor tics: rapid reflex-like intermittent movements – has attracted attention from others
– presumably seizures
- b. sequences of complex motor tics, may be difficult to separate from compulsions or stereotypies – atypical age of onset of tics (e.g., post puberty, which is unlikely for Tourette syndrome)
- c. vocal tics – seems related to stress
- d. recurrent bouts of sound – seems related to being relaxed
- e. clenching muscles – prodromal sensations
- f. complex movements – most probably drug-induced
- g. choreiform movements such as piano playing movement of fingers (noticeable in motor skill test) – relapse remitting course
– chronic course
- h. stereotypies (mostly rhythmic e.g. head-banging, hand-flapping) – progressive course
– associated with general deterioration
- i. sudden jerks
- j. ataxia
- k. orofacial dyskinesia
- l. choreoathetosis (i.e. involuntary movements in a combination of chorea (irregular migrating contractions) and athetosis (i.e. twisting and writhing)
- m. dystonia (i.e. involuntary continual muscle contractions)
- n. catatonia
- o. mutism
- p. waxy flexibility (slight resistance to positioning by the examiner)
- q. rigidity
- r. cogwheel rigidity
- s. tremor
- t. seizures

18. Gross motor problems or muscle weakness

Absolutely = 2 To some extent = 1 No = 0 Don't know = 1

- a. clumsy movements – has attracted attention from others
- b. balance problems (noted in the Romberg test) – avoids participation in sports
- c. difficulties with coordination, apparent in e.g. ball games or dancing – physically inactive
– relapse remitting course
- d. aberrant gait – chronic course
- e. difficulty climbing stairs or walking on escalators – progressive course
- f. quadriceps and/or shoulder weakness (noted in motor skill test) – associated with general deterioration

19. Poor handwriting or difficulty sketching/drawing

Absolutely = 2 To some extent = 1 No = 0 Don't know = 1

- | | |
|---|---|
| a. immature pen holding | - has attracted attention from others |
| b. deteriorated handwriting | - refuses to draw/sketch |
| c. deteriorated drawing/sketching | - illegible handwriting |
| d. cannot write | - relapse remitting course |
| e. cannot draw anything figuratively | - progressive course |
| f. better at drawing/sketching than writing | - chronic course |
| | - associated with general deterioration |

20. Altered gaze

Absolutely = 2 To some extent = 1 No = 0 Don't know = 1

- | | |
|---|---|
| a. looks terrified or violent | - has attracted attention from others |
| b. mydriasis, has generally enlarged pupils | - relapse remitting course |
| | - chronic course |
| | - associated with general deterioration |

21. Urinary tract symptoms

Absolutely = 2 To some extent = 1 No = 0 Don't know = 1

- | | |
|---|---|
| a. mictation urge | - has attracted attention from others |
| b. nervous of not making it to the bathroom when needed | - assumed to be a fixed idea |
| c. enuresis in nighttime | - requires diapers |
| d. enuresis in daytime | - relapse remitting course |
| | - chronic course |
| | - progressive course |
| | - associated with general deterioration |

-
22. Gut problems Absolutely = 2 To some extent = 1 No = 0 Don't know = 1
- a. grumbles – more difficult to treat than expected
 - b. diarrhea – requires treatment
 - c. constipation – requires daily adjustments
 - d. both constipation och diarrhea – requires inpatient care or visits to the emergency department (circle as applicable)
 - e. encopresis – relapse remitting course
 - chronic course
 - progressive course
 - associated with general deterioration

-
23. Other pain-related symptoms Absolutely = 2 To some extent = 1 No = 0 Don't know = 1
- a. menstrual pain – more difficult to treat than expected
 - b. muscle pain – requires recurrent treatment
 - c. joint pain – requires continuous treatment
 - d. headache – requires inpatient care
 - e. migraine – relapse remitting course
 - f. other pains – chronic course
 - progressive course
 - associated with general deterioration

-
24. Sleep disturbances Absolutely = 2 To some extent = 1 No = 0 Don't know = 1
- a. insomnia – has attracted attention from others
 - b. waking up during the night – requires treatment
 - c. restless sleep – relapse remitting course
 - d. night terrors – chronic course
 - e. sleep paralysis – progressive course
 - f. tired during the day – associated with general deterioration
 - g. oversleeping
 - h. falling asleep unexpectedly during the day
-

-
25. Fatigue/exhaustion Absolutely = 2 To some extent = 1 No = 0 Don't know = 1
- a. associated with stress – swift recovery after rest
 - b. extreme exhaustion lasting more than 24 hours after physical or mental strain – requires daily adjustments
 - c. extreme fatigue as in chronic fatigue syndrome – relapse remitting course
 - chronic course
 - progressive course
 - associated with general deterioration

-
26. Hyperactivity Absolutely = 2 To some extent = 1 No = 0 Don't know = 1
- a. hyperactive signs, such as swinging the legs – has attracted attention from others
 - b. moving all the time, constantly restless – is associated with anxiety
 - c. speaks a lot, difficult to interrupt – has required medication
 - d. runs back and forth – probably side-effect from drug treatment
 - relapse remitting course
 - chronic course
 - progressive course
 - associated with general deterioration

-
27. Other abnormalities Affirmed Observed No

Symptoms compilation total points (range, 0–52)

MOTOR SKILLS ASSESSMENT

Demonstrate and describe to the person how to perform each exercise.

If the patient is too young or refuses to perform the exercise, leave blank..

1. TANDEM WALK

Subject is asked to walk in a straight line for 12 feet (3 meters), heel to toe.

- 0 = no missteps after subject has completed first full step
- 1 = one or two missteps after completing first full step
- 2 = three or more missteps, grabbing to prevent falling

2. ROMBERG TEST

Subject is asked to stand with his/her feet together, eyes closed, arms stretched out, parallel to the floor, with fingers spread apart. Maintain this position for 60 seconds.

- 0 = relatively stable, minimal swaying
- 1 = marked swaying
- 2 = subject steps to maintain balance and prevent falling

3. QUADRICEPS AND/OR SHOULDER WEAKNESS

Subject is asked to hold both arms straight out in front of the body, parallel to the floor (as in Romberg Test), and keep this position for 60 seconds.

- 0 = no problems
- 1 = tendency of arms dropping
- 2 = arms drop markedly

L	R
<input type="checkbox"/>	<input type="checkbox"/>

4. ADVENTITIOUS OVERFLOW (PIANO FINGERS)

Same as Romberg Test.

- 0 = no movement of fingers, hands, or arms
- 1 = irregular fluttering movements of fingers only
- 2 = irregular fluttering movements extended to hands and/or arms

L	R
<input type="checkbox"/>	<input type="checkbox"/>

5. ALTERNATING SCISSOR JUMPS

Subject is asked to assume a starting position with the right leg and left arm in front of the body and perform 15 rhythmic scissor jumps (i.e. alternating the opposite leg/arm in front of the body as if cross-country skiing).

- 0 = no difficulty and no hesitation
- 1 = some difficulty
- 2 = major difficulty or inability

6. RAPID ALTERNATING HAND MOVEMENTS

Subject is asked to sit and place his/her hands palms down approximately 10 cm (4 in) proximally from the knees. The subject is asked to start with his/her dominant hand (usually the right hand) and slap his/her leg distinctly with the palm and back of his/her hand in an alternating motion. The subject is asked to perform the task rapidly 20 times, one hand at a time.

- 0 = no major disruption of motion, no hesitation, no mistakes in hand placement
- 1 = one or two major disruptions of motion, hesitations, or mistakes in hand placement
- 2 = three or more major disruptions of motion, hesitations, or mistakes in hand placement

L	R
<input type="checkbox"/>	<input type="checkbox"/>

7. **WHISTLE**

Subject is asked to whistle a tune for 10 seconds.

0 = no difficulty whistling a tune

1 = some difficulty whistling, cannot whistle a tune

2 = cannot whistle

8. **MILKMAID'S GRIP**

The clinician faces the subject and holds the index and middle fingers of each hand pointing down like a cow's teats. The subject is asked to grab a "teat" with each of his/her hands and maintain a steady grip for 30 seconds.

0 = even grip

1 = slightly uneven grip

2 = a "milking" motion of contraction and relaxation

L

R

9. **DERMOGRAPHISM (SKIN WRITING)**

Subject is asked to remove shirt (or pull up sleeves and shirt). Lightly scratch the skin on the arms and torso with the back of a pen.

0 = no marks

1 = signs of marks

2 = scratches redden into a raised welt similar to hives

10. **WEIGHT**

11. **HEIGHT**

COGNITIVE ASSESSMENT

Writing assignment

Copy the following sentences.

The dog is sitting in the court.

.....
.....
.....

The cookies we received were very good.

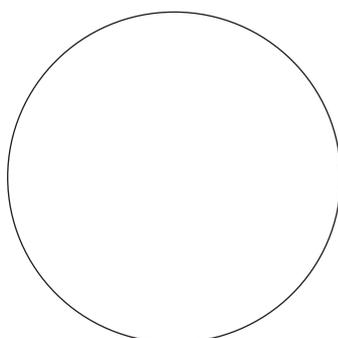
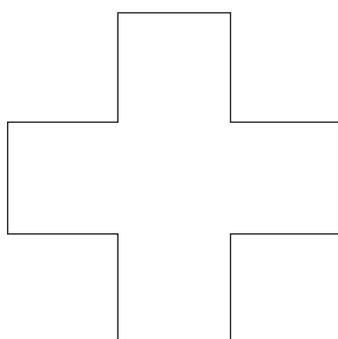
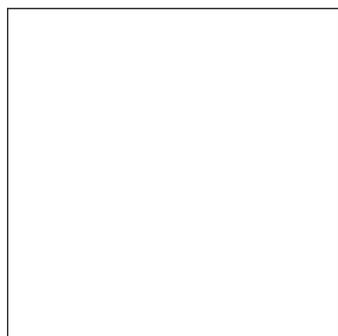
.....
.....
.....

Johnny thinks there are too many foxes in the woods around his house.

.....
.....
.....
.....
.....

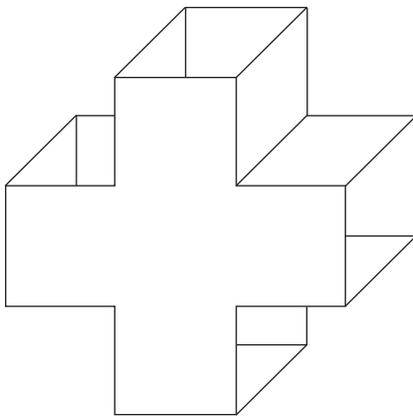
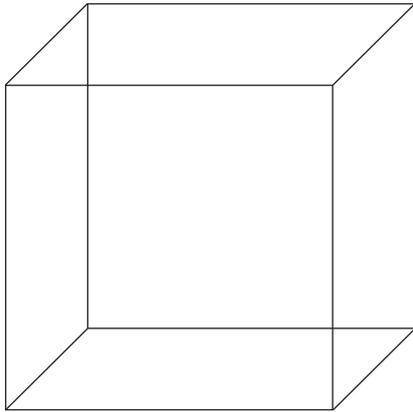
Drawing assignment 1

Copy the following shapes.



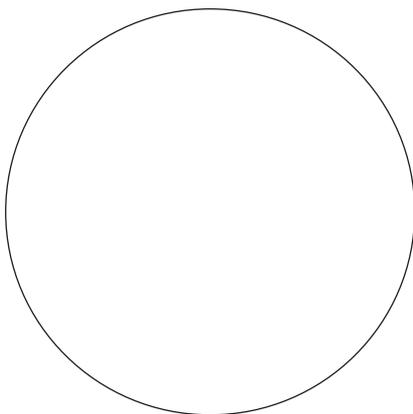
Drawing assignment 1

Copy the following shapes.



Drawing assignment 3

Fill in the numbers and hands to draw a clock showing "a quarter to five".



Drawing assignment 4

Draw a person (e.g., yourself). Use a separate sheet of paper.

SEVERITY – MENTAL SYMPTOMS (include cognitive symptoms)

	Ever	Current (past 2 weeks)
a. Severity of preexisting symptoms (before onset)
b. Severity of current index symptoms (exclude preexisting symptoms, e.g., intellectual disability)
c. Severity of regression/lost abilities
d. Severity of personality changes
e. Severity of acquired cognitive decline
<p><i>0 Not assessed 4 Moderate</i> <i>1 None 5 Marked</i> <i>2 Borderline 6 Severe</i> <i>3 Mild 7 Extremely severe</i></p>		
<i>Severity of current psychiatric symptoms, sum (range 0–35)</i>	

SEVERITY – PHYSICAL SYMPTOMS (include disordered sleep, appetite, pain, motor skills and fatigue)

	Ever	Current (past 2 weeks)
a. Severity of preexisting symptoms (before onset)
b. Severity of present index symptoms (exclude preexisting physical symptoms)
c. Severity of acquired motor skills problems
d. Severity of sleep disturbances
e. Severity of fatigue
<p><i>0 Not assessed 4 Moderate</i> <i>1 None 5 Marked</i> <i>2 Borderline 6 Severe</i> <i>3 Mild 7 Extremely severe</i></p>		
<i>Severity of current physical symptoms, sum (range 0-35)</i>	

Overall change

..... **Overall change** since being worst
 (at years of age, characterized by symptom(s))

..... **Overall change** since last visit (date)

- | | |
|----------------------------------|---------------------------|
| <i>0. Not applicable/unknown</i> | <i>4. No change</i> |
| <i>1. Very much improved</i> | <i>5. Minimally worse</i> |
| <i>2. Much improved</i> | <i>6. Much worse</i> |
| <i>3. Minimally improved</i> | <i>7. Very much worse</i> |

CLINICAL SUMMARY

Acute or sub acute onset

< 24 hrs 1–3 days 4–30 days 1–3 months > 3 months–12 months > 1 year

Focal neurological symptoms: paresis, ataxia, dystonia, chorea / athetosis, myoclonus, sensory loss, paresthesias, cranial nerve affection, sphincter dysfunction; also subtle motor symptoms that are new, such as impaired ability to write Yes No Unknown

Psychiatric symptoms: OCD or anorexia with unusually abrupt onset or psychosis with atypical features Yes No Unknown

Seizures Yes No Unknown

Dysautonomia: hyper/hypotension, tachycardia/bradycardia, hypoventilation, improper temperature control Yes No Unknown

Course

- Flares with a return to normal initially but gradual deterioration with each flare
- Progressiv course with gradual deterioration without flares
- Flares with recovery to normal
- Chronic
- Occurence of new symptoms
- Gradual improvement
- Stable recovery back to normal (since

Related to infection or fever (parainfectious or postinfectious)

Onset related to strep infection? Confirmed Likely No Unknown
 Onset related to throat problems? Confirmed Likely No Unknown
 Onset related to other infection? Confirmed Likely No Unknown
 Confirmed Likely No Unknown

Headache, vomiting, stiff neck, impaired general condition Confirmed Likely No Unknown

Related to inflammation

Has a defined inflammatory disease? Confirmed Likely No Unknown
 Improvement when having a fever? Confirmed Likely No Unknown
 Improvement from cortisone? Confirmed Likely No Unknown
 Improvement from NSAIDs? Confirmed Likely No Unknown
 Improvement from antibiotics? Confirmed Likely No Unknown
 Improvement from other treatment?

Current diagnoses: Rank the present diagnoses: primary (1), secondary (2), tertiary (3) etc.

PANS PANDAS CANS ID OCD Hoarding
 Autism spectrum disorder Psychosis NOS Schiz Bipolar ADHD
 Oppositional defiant Anorexia ARFID DCD Tics
 Depression Anxiety Separation anxiety Self-harm (NSSI)
 Emotionally unstable personality Epilepsy Stereotypies Narcolepsy
 Kleine-Levin Other sleep disorder Pain disorder Chronic fatigue IBS
 Celiac disease Rheumatic disease Inflammatory disease of the intestine Other

Reliability of the assessment as a whole

0. Excellent, no reason to suspect data is unreliable
1. Good, factor(s) present that may adversely affect reliability
2. Fair, factor(s) present that definitely reduce reliability
3. Poor, very low reliability

Criteria for some relevant diagnoses

PANDAS Pediatric autoimmune Neuropsychiatric disorders associated with streptococcal infections (Swedo et al, Am J Psychiatry 1998, 155(2): 264–271)	PANS Pediatric acute-onset neuropsychiatric syndrome (Swedo et al, Pediatrics & Therapeutics 2012, 2(2))	Idiopatisk CANS Childhood acute neuropsychiatric symptoms (Singer et al, J Pediatr 2012, 160(5): 725–731)
All five diagnostic criteria must be met: I. Presence of obsessive-compulsive disorder (OCD) or a tic disorder. II. Prepubertal symptom onset and after age of 3 years. III. Acute symptom onset and episodic (relapsing-remitting) course. IV. Temporal association between Group A streptococcal infection and symptom onset/exacerbations. V. Associated with neurological abnormalities (particularly motoric hyperactivity and choreiform movements).	I. Abrupt, dramatic onset of obsessive-compulsive disorder or severely restricted food intake. II. Concurrent presence of additional neuropsychiatric symptoms, with similarly severe and acute onset, from at least two of the following seven categories (see text for full description): 1. Anxiety. 2. Emotional lability and/or depression. 3. Irritability, aggression, and/or severely oppositional behaviors. 4. Behavioral (developmental) regression. 5. Deterioration in school performance. 6. Sensory or motor abnormalities. 7. Somatic signs and symptoms, including sleep disturbances, enuresis or urinary frequency. III. Symptoms are not better explained by a known neurologic or medical disorder, such as Sydenham chorea, systemic lupus erythematosus, Tourette disorder, or others.	Acute dramatic onset of neuropsychiatric symptoms before 18 years of age. I. Primary criterion: OCD. II. Secondary criteria: Tics, dysgraphia, clumsiness, hyperactivity, anxiety, psychosis, developmental regression, sensitivity to sensory stimuli, emotional lability. III. Either mono- or polyphasic. The proposed CANS classification does not require association with a specific organism, limitation of symptoms to tics or OCD, a specific age range, or recurrence of symptoms. It is unknown at this time whether this idiopathic category will have definable clinical features or characteristic laboratory findings.