

# PROSPER-ID\*

Pro-active health assessment instrument for people  
with intellectual disabilities

26-3-2018  
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Soon, you will answer a list of questions. It is okay if someone (family, caregiver, etc.) helps you with this.

- The questions are all about your health.
- We know that people with intellectual disabilities sometimes find it difficult to explain to others about their health.
- We have come up with 62 different questions. That is quite a lot.
- If you are tired of answering questions, you can put the questions away for a while. Only continue with the questions once you feel rested again.
- There are no good or bad answers. It is about what you find important or where you have problems.

**The completed list of questions helps your doctor (GP) to better understand what is NOT going well with your health. They can then help you to feel better again.**

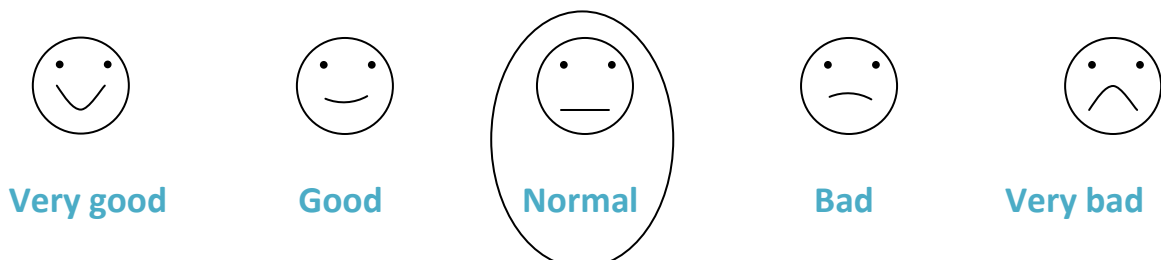
All the questions have a **black color**. The answers have a **blue color**.

Here is an example:

- Have you ever had an epileptic seizure?  YES  NO
- Tick the box of your choice. Like this:  YES  NO
- And then continue with the next question

Another example:

- How well can you see, in your opinion? (If you wear glasses, with your glasses, otherwise without)
- Put a circle around your choice. Like this:



Last example:

- Can you tell why not? **Write your answer here:**

## **A1. Seeing and hearing**

### **Seeing**

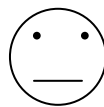
1. Do you wear glasses?

- No
- Yes

When was the last time that you were at the eye doctor, optician/glasses shop, or GP to have your eyes checked?

- I have never been there
- I have not been there in a long time
- I have been there
  - date: .....
  - I don't remember the date
- Don't know

2. In your opinion, how well can you see (with your glasses, if you wear any, or without them if you don't)?



**Very good**

**Good**

**Normal**

**Bad**

**Very bad**

3. Have you started seeing worse in the past year?

- No (continue with question 4)
- Yes (a little)
- Don't know

If YES:

Do you see worse when you look at a photobook or iPad or newspaper (up close)?

- Yes
- No

Do you see worse when you look at the TV (far away)?

Yes

No

## Hearing

4. When was the last time that you had a hearing test at the ear, nose, and throat doctor, ear doctor/hearing aid shop or GP?

I have never been there

Have not been in a long time

I have been there

O date: .....

O I don't remember the date

I don't know

5. Do you have a hearing aid?

No (continue with question 7)

Yes

6. Do you wear the hearing aid every day?

Yes

No

If NO: Can you explain why not?

**Write your answer here: .....**

7. In your opinion, how well can you hear (with your hearing aid, if you wear one, or without it if you don't)?



**Very good**

**Good**

**Normal**

**Bad**

**Very bad**

## **A2. Stomach and Bowels**

8. Sometimes, some food from your stomach comes back up into your mouth. This sometimes has a sour taste.

Does this ever happen to you?

- No
- Yes

9. Do you have trouble swallowing?

- No
- Yes

10. Do you often choke when you are drinking or eating?

- No
- Yes
- Very rarely

If YES: When this happens, do you start coughing or do you have trouble breathing or do you have trouble speaking after choking/swallowing?

- No
- Yes

11. How often do you need to poop?

- More than 2 times per day
- 1-2 times per day
- 1 time every 2 days
- 1-2 times per week
- It changes, sometimes often, sometimes not very often
- Other, namely (Write your answer here):

12. Do you have trouble pooping?

(For example: not being able to poop for a while, pressing hard, pain when pooping, blood in poop, hard poop, very thin poop, etc.)

- No (continue with question 13)**
- Yes**
- Sometimes**

If YES or SOMETIMES: **Write down the problem here: .....**

13. Has your weight changed in the last 3 months?

- Yes**
- No (continue with question 14)**
- I don't know (did not weigh myself) (continue with question 14)**

If YES: Have you gained weight (become heavier) or lost weight (become lighter)?

- Gained weight**
- Lost weight**
- My weight changes; I get heavier, then lighter again**

How many kilograms do you think you weigh? ..... kg



Created by Aleksandr Vector from Noun Project

### **A3. Peeing and sex**

14. Do you have trouble peeing?

(For example: pain when peeing, straining when peeing, peeing many times in the night, etc.)

- No (continue with question 15)**
- Yes**

If YES: **Write down the problem here:**

15. Where do you pee? (You can select more than one answer)

- Usually on the toilet**
- Usually in the diaper**
- A bottle to pee in (urinal bottle)**
- Usually in my pants**
- A tube with a peeing bag stuck to it (catheter)**

16. Have you recently had a bladder infection?

(When you have a bladder infection, you have to pee often, peeing hurts, sometimes there will be blood in the pee, and sometimes you get pills from the doctor to help you get better)

- No**
- Sometimes**
- Often**

17. Question for women: How are your periods?

(You can select more than one answer)

- I'm in menopause, so no more periods**
- Good: no problems**
- Pain in belly**
- A lot of blood loss**
- Very little blood loss**
- Other, namely (Write your answer here):**

**The doctor (GP) wants to help you stay healthy.**

**The doctor (GP) would like you to not get any diseases from unsafe sex or to get pregnant if that's not what you want.**

**The next 3 questions are about this.**

18. Have you ever had sex?

(By sex, we mean making love to a man or woman)

- No (continue with question 19)**
- Yes**

19. Do you use contraceptives/birth control?

(so that the woman does not get a baby in her belly)

(You can select more than one answer)

- No (continue with question 20)**
- Birth control pills**
- IUD**
- Contraceptive injection**
- Condoms**
- Sterilization (then you are "helped")**
- Other, namely (Write your answer here):**

20. Are you ever afraid of getting an infectious disease through sex (an STD)?

- Never**
- Sometimes**
- Regularly**
- Often**
- All the time**



#### **A4. Moving**

21. Is it easy for you to move?

- Yes, easy**
- No, (a little) difficult**

If (a little) difficult: What is difficult to do?

**Write your answer here:**

22. Did you fall in the past month?

- No (continue with question 23)**
- Yes**

If YES: How many times did you fall in the past month? ..... **times**

23. Do you have pain in your joints or in your back?

(joints are, for example, your knee, ankle, wrist, shoulder, finger, hip)

- No (continue with question 24)**
- Yes**
- Sometimes**
- I don't know**

If YES: Which joint hurts?

**Write your answer here:**

## **A5. Heart and lungs**

24. Do you have a heart problem that you were born with?  
(For example: hole in the heart, heart valve defect, etc.)

- No (continue with question 25)**
- Yes**
- I don't know**

If YES: Which one? **Write your answer here:**

25. Do you think that you have problems with your heart?



Created by Felipe Pereira  
from the Heart Project

(You can select more than one answer)

- No (continue with question 26)**
- Heart palpitations (this is when your heart starts pounding very hard, fast, and weirdly)**
- Blue color (for example, on your lips, fingers, toes)**
- Getting tired very quickly during sports and exercise**
- Chest tightness or chest pain**
- Stuffy when I lay flat in bed (I like to sleep sitting upright)**
- Other, namely (Write your answer here)**

26. Do you have problems with your breathing?

- No (continue with question 27)**
- Yes**
- Sometimes**

If YES or SOMETIMES: What do you suffer from?

(You can select more than one answer)

- Coughing**
- Stiffness/not getting air**
- Wheezing**
- Other, namely (Write your answer here):**

27. Do you have one or more lung infections every year?

No

Yes

28. People who suffer from sneezing, stuffiness, itching, hay fever may be allergic.

Do you suffer from any of these things?

No

Yes, sometimes

## **A6. Epilepsy, sleep, pain**

29. Do you ever have a seizure/epileptic seizure?

- No (continue with question 30)**
- Yes**
- I have had it in the past**

If YES: Have the epileptic seizures lately....

- Become worse**
- Become less frequent**
- Remained the same**

30. Are you still able to do everything that you used to do? (For example: writing, taking the bus on your own, shopping for groceries by yourself, working, walking, being alert, etc.)

- No**
- Yes (continue with question 31)**

If NO: Can you describe the change?

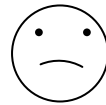
**Write your answer here:**

31. Do other people in your surroundings notice that you can do less than before? (If you're not sure, ask someone)

- No (continue with question 32)**
- I don't know (continue with question 32)**
- Yes**

If YES: What is it that they notice about you? **Write your answer here:**

32. How well can you usually remember things?  
(For example, is it easy for you to learn new things)



Very good

Good

Normal

Bad

Very bad

33. Do you notice any changes with remembering things?

No (continue with question 34)

Yes

If YES: Do you forget things:

More often

Less often

34. Are you taking any medicine to be able to sleep well?

No

Yes

How are you sleeping?



Very good

Good

Normal

Bad

Very bad

Or

It Changes

One day/period and the other day/period



Good



Bad

If you have filled in BAD or VERY BAD. Are you having trouble with:  
(You can select more than one answer)

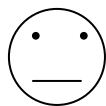
- Falling asleep**
- Sleeping through the night/waking up during the night**
- Waking up early**
  
- Sleep apnea (very loud snoring and sometimes even not breathing while sleeping)**

35. Do you have pain?

(Here, we mean pain that is MORE THAN a little headache)

- No (continue with question 36)**
- Yes**
- I don't know**

If YES: How much?



**No pain**

**A bit of  
pain**

**Regular pain**

**A lot of  
pain**

**Severe  
pain**

**Terrible  
pain**

Where does it hurt? (For example, in your knee, belly, back, shoulder, fingers, leg, etc.) **Write your answer here:**

36. Have you been to the dentist in the past year (cleaning and checking your teeth)?

- No**
- Yes (continue with question 37)**

If NO: Can you tell us why not?

- I don't have any of my own teeth anymore
- I have artificial teeth.
- It is too stressful
- I'm afraid of the dentist
- Other, namely: (Write your answer here):

## **B. Behavior**

37. Has your behavior (anger, pounding, sad, emotional) changed in recent times? (For example: have you not been feeling very comfortable in your own skin lately?)

- No (continue with question 38)**
- Yes**

If YES, has your behavior gotten

- Better**
- Worse**

If it has BECOME WORSE, **write here what has become worse:**

38. Examples of psychiatric illnesses/mental disorders are:

- anxiety
- AD(H)D (= very active/chaotic behavior),
- psychosis (hearing voices/getting commands)
- depression (very sad feeling)
- schizophrenia
- autism

Have you ever been diagnosed with a psychiatric illness?

- No (continue with question 39)**
- Yes**
- I don't know (continue with question 39)**

If YES: What was that illness? **Write your answer here:**



### **C. Population study**

39. For WOMEN only: Do you have any problems with your breasts?

- No (continue with question 40)**
- Yes**

If YES: What are those problems?

(You can select more than one answer)

- Pain**
- Bumps/lumps**
- Redness/irritation/itch**
- Retracted nipple**
- Other, namely: (Write your answer here):**

40. For WOMEN only: Are you older than 50 years?

- No (continue with question 41)**
- Yes**

Every two years, all women between the ages of 50-75 get an invitation for a breast cancer screening/mammogram

If YES: Did you ever get an x-ray (mammogram) of your breasts?

- Yes (continue with question 41)**
- No**

If NO: Can you tell us why you did not go?

- It is too stressful**
- I did not receive an invitation**
- Other, namely: (Write your answer here):**

41. Question for MEN and WOMEN

Are you older than 55 years?

- No (continue with question 42)**
- Yes**

Every two years, all men and women between the ages of 55-75 receive an invitation for a colon cancer screening.

Have you participated in this colon cancer screening?

- Yes (continue with question 42)**
- No**

If NO: Why have you not participated?

- It is too stressful**
- I did not receive an invitation**
- Other, namely: (Write your answer here):**

42. Question for MEN and WOMEN:

Have you had immunizations/vaccinations/injections?  
(See examples below)

- No**
- Yes**
- I don't know (continue with question 43)**

If YES: Which one?

(You can select more than one answer)

- All vaccinations as a baby/toddler/preschooler/school child**
- D(K)TP**
- Tetanus**
- Jaundice/Hepatitis B**
- Flu Shot/Influenza**
- HPV (cervical cancer)**
- Other, namely (Write your answer here)**
- I don't know**

If NO: Why haven't you had any vaccinations?

- It is too stressful**
- I'm afraid of injections**
- I did not receive an invitation**
- Other, namely: (Write your answer here):**

## D. Lifestyle

Try to answer honestly. It's important for the doctor (GP) to know whether you smoke, drink alcohol, or use drugs.

43. Do you smoke or have you smoked before?

- No, I have never smoked
- I used to smoke
- Sometimes 1 cigarette
- Yes, I smoke

44. Do you drink alcohol such as beer, wine, hard alcohol (Bacardi, rum, whiskey) at least 1x per week?

- No (continue with question 45)
- I sometimes drink alcohol at a party (continue with question 45)
- Yes

If YES:

How often do you drink beer, wine, or hard alcohol during the week?

**Answer: ..... days per week**

How many glasses/bottles do you drink per day?

**Answer: ..... glasses/bottles per day**

45. Do you use or have you ever used drugs?

(Drugs are, for example, weed, joints, cocaine, MDMA/ECSTASY pills, marijuana, etc.)

- No (continue with question 46)
- Yes

If YES: Which drug? **Write your answer here:**

46. Moving and doing sports include hiking, cycling, swimming, horseback riding, and exercising at home.

Moving also includes, for example, vacuuming, washing windows, working in the garden.

Do you do sports and/or move?

- Often (more than 30 minutes every day)
- Regularly (every day, but less than 30 minutes)
- Sometimes (on 2-6 days per week)
- Very rarely (once per week)
- No

47. Vitamin D and exercise is important to make your bones strong. Your body makes vitamin D when you are outside.

How often do you go outside during the day?

- Every day
- A few times per week
- Once per week
- Never or almost never

48. It is important to eat and drink healthy. Select below what you eat:

- I only get fed through a tube (continue with question 49)

#### Fruit

- every day
- a couple times per week
- once per week
- never or almost never

#### Vegetables

- every day
- a couple times per week
- once per week
- never or almost never

#### Bread or cereals or porridge

- every day
- a couple times per week
- once per week
- never or almost never

#### Tea and/or coffee

- every day
- a couple times per week
- once per week
- never or almost never

#### Water

- every day
- a couple times per week
- once per week
- never or almost never

Milk, yoghurt, buttermilk

every day  a couple times per week  once per week  never or almost never

Coke, Fanta, Seven Up, soft drinks with bubbles

every day  a couple times per week  once per week  never or almost never

Fries, hamburger, pizza, crisps

every day  a couple times per week  once per week  never or almost never

Do you have any more comments about the food you eat? If so, write them here:

## **E1. Work, free time, and friends**

49. With meaningful/nice daily activities we mean going to work, to day care, to school, or to do voluntary work.

Do you have nice daily activities?

- No
- Yes

50. Everyone needs friends and family.

Which people do you have to help you?

(You can select more than one answer)

- Parents (father, mother)
  - In-laws (brothers-in-law, sisters-in-law)
  - Brothers or sisters
  - Husband or wife (spouse)
  - Fiancé/partner/boyfriend/girlfriend
  - Neighbor
  - Friends
  - Volunteers
  - caregivers
  - Other, namely: (Write your answer here):
- 
- I have no one to help me

## **E2. Other**

51. I use:

(You can select more than one answer)

- Hearing aid**
- Glasses**
- Walking stick**
- Rollator/walker**
- Wheelchair**
- Mobility scooter**
- No aid**
- Other, namely (Write your answer here):**

52. Do you need help throughout the day?

- No (continue with question 53)**
- Yes**

If YES: What do you need help with?

(You can select more than one answer)

- Everything**
- Or (tick box)
- Grocery shopping**
- Taking a shower and getting dressed**
- Eating**
- Going to the toilet**
- Cooking dinner**
- Cleaning the house**
- Washing clothes**
- Making phone calls**
- Travelling**
- Making appointments**
- Psychological support**
- Other, namely (Write your answer here):**



53. Communication (= telling) is very important. With communication, we mean making things clear by asking questions, understanding answers, and telling what you like and what you don't like. Most people communicate by talking, others use tools to "talk".

How do you make things clear?

(You can select more than one answer)

- Talking with words**
- Voice synthesizer**
- Signs (sign language)**
- Using pictograms/cards with images**
- Body language**
- Use of objects (For example, showing swimsuit if you are going swimming)**
- Other, namely (Write your answer here):**

## **F1. Care providers**

54. Your doctor (GP) is a care provider, just like your dentist. The same goes for doctors in the hospital, social workers, behavioral experts, physiotherapists, and counsellors.

Which (professional) care providers are important to you?

<b><u>Counsellor</u></b>	<b><u>Name</u></b>
<b>(Personal) caregiver</b>	
<b>Outpatient counsellor</b>	
<b>Behavioral therapist/psychologist Remedial educationalist</b>	
<b>Doctor for people with intellectual disabilities (ID physician)</b>	
<b>Physiotherapist</b>	
<b>Dentist</b>	
<b>Social worker</b>	
<b>Occupational therapist</b>	
<b>Specialist from the hospital</b>	1.  2.

	3. 4.
<b>Other, namely:</b>	

## **F2. Personal questions**

55. Where do you live?

- A home for people with disabilities (with 24-hour care)**
- A home for people with disabilities (without 24-hour care)**
  - ..... hours of care per day/per week
  - I don't know the number of hours of care
- A house with my family**
- I have my own house and I get outpatient care**
  - ..... hours of care per day/per week
  - I don't know the number of hours of care
- Other, namely (Write your answer here):**

56. Sometimes you need help with making important decisions in areas such as health or finances. When it comes to health, the doctor (GP) needs to know who to consult with.

Who is helping you? (You can select more than one answer)

- Curator (deals with personal and financial matters)**
- Mentor (deals with personal matters, such as health)**
- Administrator (deals with financial matters)**
- Legal representative**
- Family**
- I don't know**

What is his/her name?

**Write the name and phone number of this person here:**

57. Sometimes people get a bit confused and can hurt themselves, others, or things. The law can then protect them against themselves. The judge will give them a legal status.

Do you have such a legal status? Please select one or more of the following options:

- Judicial authorization**
- Detention in a specialized facility**
- Article 60 (Often for people with severe intellectual disabilities who are not able to communicate whether they want something or not)**
- No**
- I don't know**

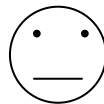
58. I think my health is:



**Extremely  
good**



**Quite good**



**Good**



**Okay**



**Bad**

Over the past weeks, my health has:

- Improved**
- Become worse**
- Remained the same**
- I don't know**

59. Has your degree of intellectual disability ever been tested with, for example, an IQ test?

- No (continue with question 60)**
- Yes**
- I don't know**

Can you tell me what level has been determined?

- Borderline (IQ 70-85, level of development 12-16 yrs.)**
- Mild (IQ 50-70, developmental age: 7-12 yrs.)**

- Moderate (IQ 35-50, developmental age: 4-6 yrs.)
- Severe (IQ 20-35, developmental age: 2-3 yrs.)
- Profound (IQ 0-20, developmental age: 0-1 yrs.)
- I don't know

60. Is the cause of your intellectual disability known?

(Causes include, for example, Down syndrome, autism, oxygen deficiency at birth)

- No (continue with question 61)
- Yes
- I don't know

If YES: What is the cause? **Write your answer here:**

### **F3. Illnesses that occurs in your family**

61. Does anyone in your family have one of the following illnesses?  
(Family = parents, grandfather/grandmother, brother/sister, aunt/uncle)

Diabetes:

No  Yes  I don't know

Psychiatric/Mental illnesses:

(For example: (AD(H))D (= very active/chaotic behavior), psychosis (hearing voices), depression (very sad feeling)

No  Yes  I don't know

Cardiovascular diseases:

No  Yes  I don't know

Epilepsy:

No  Yes  I don't know

Breast cancer:

No  Yes  I don't know

Colon cancer:

No  Yes  I don't know

Intellectual disability:

No  Yes  I don't know

## G Medication

62. Your doctor (GP) wants to know which medications you are using.

**If you have a current medication list from the pharmacy, you can also take this with you.**

**For any medications that are not on this list, please write these here below.**

In addition to medications that have been prescribed by a doctor, you maybe also use other medicines that you bought on your own, such as homeopathic remedies, pain killers (paracetamol) or food supplements.

For those medicines that you use and that are not on the pharmacy list, can you please fill in the scheme below?

Name Medicine	Quantity: number of mg or tablets	How many times per day	Do they work well?	Do you know what this medicine is for?



--	--	--	--	--

Do you also use psychotropic drugs?

(For example, risperidone, dipiperon, anti-depressants (e.g. citalopram) or Ritalin)

- No
- Yes
- I don't know

If YES: What is the name of this medicine?

**Write your answer here:**

**This was the last question. Thank you so much for completing this list of questions. Take this completed list with you to your doctor.**

## **H. Own questions for the doctor**

Below, you can write down any questions you have for your doctor.

1.

2.

3.

# I. Physical and supplementary research by the general practitioner

(To be completed by the general practitioner)

## 1. General impression (consider the following points):

- a. appearance – physical characteristics;
- b. age estimation;
- c. self-care;
- d. contact – eye contact;
- e. attitude
- f. possibly behavior towards others;
- g. presentation of complaints;
- h. Other, namely:

## 2. Awareness (circle):

clear/focused   confused   inadequate   unintelligible   apathic/no contact

## 3. Communication (tick box):

- talking: whole sentences
- talking: loose words
- voice synthesizer
- sign language
- use of pictograms/photos
- through body language
- Other, namely...

## 4. Dismorphology (describe):

## 5. Impression of the hearing (use for example the whisper map)

- 6. **Otoscopy**                      AS                      AD
- 7. **Length**                              cm
- 8. **Weight**                              kg
- 9. **BMI**
- 10. **Blood pressure**                      mmHg
- 11. **Pulse**                              /min.                      regular/irregular                      evenly: yes/no
- 12. **Heart auscultation**                      S1S2:                      Souffles:                      Additional tones:

13. **Physical examination with regard to the points that have emerged from the anamnestic questionnaire**

14. **Indication for additional blood tests?**            **Yes**            **No**

15. **Indication for additional urine analysis?**            **Yes**            **No**

16. **Referrals necessary?** (circle or describe)

- a. **Vision test**            **Yes**            **No**
- b. **Hearing test**            **Yes**            **No**
- c. **Clinical genetics**            **Yes**            **No**
- d. **Other, namely .....**

17. **Reanimation policy discussed?**            **Yes**            **No**

18. **Treatment limitations discussed?**            **Yes**            **No**            **n/a**

19. **Are any freedom-limiting measures being applied?** (For example: locked doors, mandatory medication administration, mandatory food administration)

**Yes**            **No**

## Action plan for the patient and counsellors

In response to the questionnaire and the physical examination, we have made the following agreements:

1.

This action is performed by:

2.

This action is performed by:

3.

This action is performed by:

4.

This action is performed by:

5.

This action is performed by: