

Questionnaire

This questionnaire consists of ten different categories, shared among the panellists in the patient panel. Each category, as well as the name of the interviewer, is shown in the orange header.

Please note that the questionnaire is intended as a guideline to initiate a conversation rather than an interview. It will not always be necessary to literally ask all the questions in the questionnaire. And feel free to ask an additional question if you wish!

| Minimum number of patients | [name of panellist] |
|--|---------------------|
| ❖ When was the care for [disorder] started in the centre? | |
| ❖ What physicians are involved in the care for patients with [disorder]? | |
| ❖ How many patients with [disorder] visited the centre in the past year? | |
| ❖ How many new patients visited the centre in the past year? | |
| ❖ How do patients find their way to the centre? | |

| Specific diagnostics | [name of panellist] |
|---|---------------------|
| ❖ How is the course of treatment for a new patient started at the centre? | |
| ❖ Which medical examinations are performed as part of the diagnostic procedure? | |
| ❖ Can all these medical examinations be performed at the centre? | |
| ❖ What makes this centre unique in the Netherlands as regards the diagnostics for [disorder]? | |
| ❖ On average, how long does it take before a patient gets his diagnosis at the centre? | |

Multidisciplinary approach

[name of panellist]

- ❖ What is the course of treatment after a patient has received his diagnosis?
- ❖ Who is the primary physician?
- ❖ Does the patient see the same physician each time?
- ❖ Which specialists are involved in the patient's treatment?
- ❖ How much time is made available for the first visit? And for the follow-up visits?
- ❖ What is the frequency of visits to the centre of expertise after a patient has been diagnosed?
- ❖ Can the patient see all the specialists involved in his treatment during one follow-up visit?
- ❖ Is the course of treatment described in a clinical pathway or protocol?
If so, what are the components of the pathway/protocol?
- ❖ Are there structural patient discussions at the centre?
- ❖ How often do these discussions take place? Which specialists are involved?
- ❖ Is the psychological aspect of the [disorder] included in the course of treatment at the centre?
If so, how is this done?
- ❖ Is psychological/social assistance offered routinely?
If so, at which time during the course of treatment?

Transition from paediatric care to adult care

[name of panellist]

- ❖ How is the transition from paediatric care to adult care organised at the centre?
- ❖ At what age does transition from paediatric care to adult care take place?
- ❖ Is the transition procedure laid down in a protocol?
If so, what does this protocol look like?

Accessibility

[name of panellist]

- ❖ How can patients contact the centre?
- ❖ How can the centre be contacted outside office hours/in case of emergency?
- ❖ How are patients informed on how they can reach the centre (by letter/a small map)?
- ❖ Do patients have one main point of contact?
If so, which specialist is the main point of contact for children and which specialist for adults?
- ❖ How can patients reach their main point of contact?

Regional health care

[name of panellist]

- ❖ Which regional healthcare providers do patients with [disorder] need to see?
- ❖ How do you collaborate with these care providers?
- ❖ What type of care does a patient receive at the centre of expertise? What type of care could also be offered at a regional healthcare facility?
- ❖ How does the centre collaborate with regional care facilities?
- ❖ How does the mutual collaboration between the centres of expertise take place?
- ❖ How is the patient's general practitioner involved?
- ❖ Do you also coordinate any regional health care?
If so, how do you coordinate this care?
If not, who does coordinate this care?
- ❖ Does the coordinator/primary physician keep a record of all the regional care patients with [disorder] need?

Education

[name of panellist]

- ❖ Does the department staff include a professor?
- ❖ What training courses in the field of [disorder] are you involved in?
- ❖ How do you facilitate education as part of these training courses?
- ❖ Do you also involve patients in teaching? Patients may for example be invited to attend lectures to tell their story.
- ❖ Do you also facilitate training for care providers within or outside the centre of expertise?
- ❖ Does the centre organise national or international conferences?
- ❖ Do you participate in national and international conferences?
- ❖ How do you ensure that the expertise in [disorder] is maintained at the centre?

Scientific research

[name of panellist]

- ❖ Are you involved in scientific research? Can you give some examples?
- ❖ Is your centre involved in the development of new treatments/surgical techniques? Can you name a few examples?
- ❖ Which national and international sites do you collaborate with in the field of scientific research?
- ❖ Which specialists/PhD students does the team that is involved in scientific research consist of?
- ❖ How many publications on [disorder] did you get published in the past 5 years?
- ❖ How does the centre obtain funding for research?
- ❖ How are patients with [disorder] informed about the research results?

Registration

[name of panellist]

- ❖ Is your centre involved in any national or international registries?
If so, which registries?
- ❖ What data are recorded in these registries?
- ❖ Does the centre itself own a registry?
If so, what data are recorded in this registry?
- ❖ Do you store body materials in biobanks? E.g. skin biopsies, etc.
- ❖ In what way are patients involved in the registry?
- ❖ Do you inform patients about research results in relation to the registry?
If so, how do you inform your patients?
- ❖ How should, in your opinion, a registry be given shape?

Patient organisations

[name of panellist]

- ❖ Which patient organisations do you cooperate with?
- ❖ How do you stay in contact with the patient organisations?
- ❖ How do you cooperate with the patient organisations? E.g. do you give presentations or do you organise patient days, do you assist in the writing of informational material, etc.
- ❖ How do you inform the patient organisations about relevant developments?
- ❖ Do you have structural meetings with the patient organisations?
- ❖ How do you inform patients about the existence of patient organisations?
- ❖ What are the main tasks of the patient organisation in your opinion?
- ❖ What is the added value of the patient organisation in your opinion?

Suggestions for improvement

[name of panellist]

- ❖ Do you have any suggestions for improvement regarding the care you receive?