

Expertise Mapped

Do you want to help improve the visibility around the care for your disorder? Then please fill out this questionnaire and indicate what is important to you. Your experience is important!

This questionnaire is part of the project 'Expertise Mapped'. The purpose of this project is to map the organisation of care for rare diseases. Several patient organisations cooperate in this project.

The project consists of three stages:

- Stage 1: Using the questionnaire we ask you about your healthcare experiences in relation to your disorder.
- Stage 2: We will lead a discussion between a patient panel and expert physicians in the field of your disorder.
- Stage 3: The information from stages 1 and 2 is summarised in a special knowledge map. The knowledge map shows, from the patient's perspective, which knowledge can be found where.

For more information about this project and the knowledge maps, please visit:

www.expertiseinkaart.nl / www.expertisemapped.org

General

If you fill out this questionnaire for someone other than yourself, we would like to ask you to answer all questions with this person in mind. For instance, when you answer the question: "What is your gender?" you will indicate the gender of the person for whom you are filling out the questionnaire.

For whom are you filling out this questionnaire?

- Yourself
- Your partner
- Your child
- Other,

What is your gender? (Please indicate the gender of the person for whom you are filling out the questionnaire)

- Male
- Female

What is your year of birth? (Please indicate the year of birth of the person for whom you are filling out the questionnaire)

Enter your answer here:

Diagnosis

Have you received a diagnosis?

- Yes
- No

If yes, which disorder has been diagnosed?

.....

What were the first signs of your disorder?

Select all that apply:

- Fatigue
- Fever
- Cold
- Coughing
- General malaise
- Other:

How long did it take before you received your diagnosis?

- Less than half a year
- Half a year to one year
- More than one year

How long has it been since you were diagnosed?

- Less than one year ago
- 1-3 years ago
- 3-5 years ago
- More than 5 years ago

Which healthcare providers did you visit in order to get diagnosed?

Select all that apply:

- Cardiologist
- Physician at child health centre
- Dermatologist
- Dietician
- Endocrinologist
- Physical therapist
- General practitioner
- Internist
- Paediatrician
- Clinical geneticist
- ENT specialist
- Pulmonologist

- Gastroenterologist
- Nephrologist
- Neurologist
- Plastic surgeon
- Rheumatologist
- Other:

Which specialist made the diagnosis?

Name of specialist:

Specialisation:

Hospital:

UMC

Are you currently visiting a University Medical Centre (UMC) for your disorder? (If you visit more than one UMC please indicate the UMC you visit most often)

- AMC – Amsterdam
- VUmc – Amsterdam
- Erasmus MC – Rotterdam
- LUMC – Leiden
- UMCU – Utrecht
- Radboud UMC – Nijmegen
- UMCG – Groningen
- MUMC+ – Maastricht
- I do not visit a UMC

Which specialist(s) do you visit in this UMC?

Select all that apply:

- Cardiologist
- Dermatologist
- Endocrinologist
- Gynaecologist
- Haematologist
- Internist
- Pulmonologist
- Paediatrician
- Clinical geneticist
- ENT specialist
- Gastroenterologist
- Metabolic disease physician
- Nephrologist
- Neurologist
- Ophthalmologist
- Plastic surgeon

- Rheumatologist
- Rehabilitation specialist
- Other:

Do you think the UMC has sufficient knowledge about your disorder and treatment?

- Yes
- No
- I don't know

How many times a year do you visit this UMC?

- Once a year
- 2-4 times a year
- More than 4 times a year

What is the distance between your place of residence and this UMC?

- Less than 50 km
- Between 50 and 100 km
- Between 100 and 200 km
- Over 200 km

Do you have a single point of contact for your disorder within the UMC?

- Yes
- No

Who is your point of contact within the UMC?

Name:.....

Specialisation:.....

Do you feel your point of contact within the UMC takes sufficient time to answer your questions?

- Yes
- Sometimes
- No

Regional hospital

Do you currently visit a regional hospital for your disorder?

- Yes
- No

Which regional hospital? (If you visit more than one regional hospital please indicate the regional hospital you visit most often)

Name of hospital:

Location of hospital (city, town):

Which specialist(s) do you visit in this regional hospital?

Select all that apply:

- Cardiologist
- Dermatologist
- Endocrinologist
- Gynaecologist
- Haematologist
- Internist
- Pulmonologist
- Paediatrician
- Clinical geneticist
- ENT specialist
- Gastroenterologist
- Metabolic disease physician
- Nephrologist
- Neurologist
- Ophthalmologist
- Plastic surgeon
- Rheumatologist
- Rehabilitation specialist
- Other:

How many times a year do you visit this regional hospital?

- Once a year
- 2-4 times a year
- More than 4 times a year

What is the distance between your place of residence and this regional hospital?

- Less than 50 km
- Between 50 and 100 km
- Between 100 and 200 km
- Over 200 km

Do you think the regional hospital has sufficient knowledge about your disorder and treatment?

- Yes
- No
- I don't know

Do you have a single point of contact for your disorder within the regional hospital?

- Yes
- No

Who is your point of contact within the regional hospital?

- Name:.....
- Specialisation:.....

Do you feel your point of contact within the regional hospital takes sufficient time to answer your questions?

- Yes
- Sometimes
- No

Do you think there is good coordination between the UMC and the regional hospital about your treatment?

- Yes
- No
- I don't know

Centre of expertise

Do you believe there is a centre of expertise for your disorder?

- Yes, the UMC I entered
- Yes, the regional hospital I entered
- Yes, a hospital that has not been mentioned in this questionnaire
- No
- I don't know

If you answered 'yes' in the previous question, which hospital is this centre of expertise?

Name of centre of expertise:

Location of centre of expertise (city, town):

According to you, which specialist is the expert in the field of your disorder?

Name of specialist:

Specialisation:.....

Hospital:.....

Are you currently being treated at/visiting the centre of expertise?

- Yes
- No

Do you think the centre of expertise has sufficient knowledge about your disorder and treatment?

- Yes
- No
- I don't know

How many times a year do you visit this centre of expertise?

- Once a year
- 2-4 times a year
- More than 4 times a year

What is the distance between your place of residence and this centre of expertise?

- Less than 50 km
- Between 50 and 100 km
- Between 100 and 200 km
- Over 200 km

Do you have a single point of contact for your disorder within the centre of expertise?

- Yes
- No

Who is your point of contact within the centre of expertise?

Name:.....

Specialisation:.....

Do you feel the point of contact within the centre of expertise takes sufficient time to answer your questions?

- Yes
- Sometimes
- No

Communication

Which healthcare providers do you visit for your disorder next to the previously mentioned physicians?

Select all that apply:

- Dietician
- Occupational therapist
- Physical therapist
- Healthcare providers at the institution (where I stay)
- Speech therapist
- Social worker
- Psychologist

- District nurse/home care
- None
- Other:

Do you think there is sufficient coordination and communication among the different healthcare providers?

- Yes
- No
- Other, namely:.....

How important is it to you to have access to a specialist?

- I am always willing to travel the whole country/Netherlands so that I can see an expert in the field of my disorder.
- I am only willing to travel the whole country/Netherlands for a yearly consult with an expert in the field of my disorder.
- I find it more important to have a specialist nearby, even if he has less expertise in the field of my disorder.
- Other:

How important is it to you to have a single point of contact within the hospital?

- Very important
- Important
- Not important
- Absolutely not important

Are you in transition, or have you experienced the transition from paediatric care to adult health care?

- Yes
- No

If you answered 'yes' in the previous question, how did you experience this transition?

- Positive
- Neutral
- Negative

Are you registered in an (inter)national research database as a patient?

- Yes, I am registered
- No, I am not registered
- I don't know whether I am registered

Which scientific aspect in relation to your disorder do you value the most? Rank the options below, where 1 is the most important and 3 the least important aspect.

- ___ To be registered in a research database as a patient
- ___ Scientific research into the disorder
- ___ Training of specialists in the disorder

Wishes and needs

Do you experience problems with respect to the care related to your disorder?

- Yes
- No

If you answered 'yes' in the previous question, which problems do you experience with healthcare providers in the care for your disorder?

Select all that apply:

- Lack of knowledge
- High administrative burden
- Long waiting times in the waiting room
- Difficult accessibility (transportation)
- Repeated physical examinations
- Contradictory advice
- Lack of cooperation, consultation and transfer of patient data
- Insufficient compensation for drugs, medical devices and other medical supplies
- Other:

With which healthcare provider has a lack of knowledge?

Select all that apply:

- The general practitioner
- The specialist in the UMC
- The specialist in the regional hospital
- Other healthcare providers

With which healthcare provider do you experience a high administrative burden?

Select all that apply:

- The general practitioner
- The specialist in the UMC
- The specialist in the regional hospital
- Other healthcare providers

With which healthcare provider do you experience long waiting times in the waiting room?

Select all that apply:

- The general practitioner
- The specialist in the UMC
- The specialist in the regional hospital
- Other healthcare providers

With which healthcare provider do you experience difficult accessibility (transport)?

Select all that apply:

- The general practitioner
- The specialist in the UMC
- The specialist in the regional hospital
- Other healthcare providers

With which healthcare provider do you experience repeated physical examinations?

Select all that apply:

- The general practitioner
- The specialist in the UMC
- The specialist in the regional hospital
- Other healthcare providers

With which healthcare provider do you experience contradictory advice?

Select all that apply:

- The general practitioner
- The specialist in the UMC
- The specialist in the regional hospital
- Other healthcare providers

With which healthcare provider do you experience lack of cooperation, consultation and transfer?

Select all that apply:

- The general practitioner
- The specialist in the UMC
- The specialist in the regional hospital
- Other healthcare providers

With which healthcare provider do you experience insufficient compensation for drugs, medical devices and other medical supplies?

Select all that apply:

- The general practitioner
- The specialist in the UMC
- The specialist in the regional hospital
- Other healthcare providers

Do you feel sufficiently supported in organising and coordinating the care around your disorder?

- Yes
- No

Explain your answer:.....

Do you feel sufficiently supported in the psychological aspects of life with your disorder (such as the opportunity to be referred to a psychologist or social worker)?

- Yes
- No

Explain your answer:.....

Do you feel a need for support?

- Yes
- No

From whom would you like to get this support?

- The general practitioner
- The specialist in the UMC
- The specialist in the regional hospital
- Other:

Finally

Possible questions and/or remarks can be given here:

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

Are you interested in taking part in the patient panel and entering into a dialogue with the specialists? More information about the patient panel can be found here. Have you become enthusiastic about the Knowledge Map? Then fill in the details below so that we can contact you!

Name:.....
E-mail:.....
Telephone:.....
Place of residence:.....

Thank you

We would like to thank you very much for filling out the questionnaire. The results will be incorporated in the dialogues between patients and specialists. With the results from this questionnaire and the dialogues we hope to visualise where most knowledge about each disease is concentrated. This overview will be presented in a special knowledge map. More information on this project can be found at www.expertisemapped.org.

Click on the send button to finish the questionnaire.
