

OVAMA questionnaire

This questionnaire is intended for patients with a vascular malformation and assesses the symptoms they may experience. 'Vascular malformation' is the medical term for a group of congenital vascular anomalies.

General symptoms scale

1. General problems

How often did your vascular malformation bother you in the past 4 weeks?

- Never
- Less than once a week
- On average once a week
- Several times a week
- Every day

2. General problems

How much did your vascular malformation bother you in the past 4 weeks?

- Not at all
- A little bit
- Moderately
- A lot
- Extremely

3. Pain because of the vascular malformation

In the past 4 weeks ...

- I did not have this problem
(go to question 4)

- I had this problem

↓

If you had this problem:

A. How often did you have pain in the past 4 weeks?

- Less than once a week
- About once a week
- Several times a week
- Every day

B. If you were in pain, how severe was this on average in the past 4 weeks?

0 – 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10

No pain

Most severe pain
imaginable

4. Bleeding because of the vascular malformation

In the past 4 weeks ...

- I did not have this problem
(go to question 5)

- I had this problem

↓

If you had this problem:

A. How often did you have bleeding episodes in the past 4 weeks?

- Less than once a week
- On average once a week
- Several times a week
- Every day

B. How long did these bleeding episodes last?

- The bleeding stopped within a minute
- The bleeding stopped within 5 minutes
- The bleeding stopped but lasted longer than 5 minutes
- The bleeding could not be stopped without medical assistance

5. Leakage of fluid (other than blood) from the vascular malformation

In the past 4 weeks ...

I did not have this problem
(go to question 6)

I had this problem

↓

If you had this problem:

A. How often did the vascular malformation leak fluid in the past 4 weeks?

- Less than once a week
- On average once a week
- Several times a week
- Every day

B. If the vascular malformation leaked fluid, how much did this bother you?

- Not at all
- A little bit
- Moderately
- A lot
- Extremely

6. Temporary enlargement of the vascular malformation

For example: after exercise, in warm weather or in a certain pose.

In the past 4 weeks ...

I did not have this problem
(go to question 7)

I had this problem

↓

If you had this problem:

A. How often did you experience enlargement of the vascular malformation in the past 4 weeks?

- Less than once a week
- About once a week
- Several times a week
- Every day

B. If the vascular malformation enlarged, how much did this bother you?

- Not at all
- A little bit
- Moderately
- A lot
- Extremely

Appearance scale

The following questions are about the appearance of the vascular malformation. If the vascular malformation has completely disappeared (for example after surgical removal), please assess the spot where the vascular malformation used to be.

1. Size of the vascular malformation

How large is your vascular malformation?

- Very small
- Small
- Medium size
- Large
- Very large

2. Visible swelling/mass

Do you have a visible swelling or mass of the vascular malformation?

0 – 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10
No visible swelling Small swelling Medium swelling Large swelling Very large swelling

3. Color of the vascular malformation

Is the color of the vascular malformation different from that of your normal skin?

0 – 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10
Not at all Slightly different Moderately different Very different Extremely different

4. Surface/texture of the vascular malformation

Is the surface/texture of the vascular malformation different from your normal skin? For example irregular, rough, or bumpy.

0 – 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10
Not at all Slightly different Moderately different Very different Extremely different

5. Alteration of facial features

Do you find that your face looks different or distorted because of the vascular malformation?

0 – 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10
Not at all Slightly distorted Moderately distorted Very distorted Extremely distorted

6. Alteration of bodily features

Do you find that your body (except your face) looks different or distorted because of the vascular malformation?

0 – 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10
Not at all Slightly distorted Moderately distorted Very distorted Extremely distorted

7. Staring

Do other people stare at you because of your vascular malformation?

- Not at all
- Rarely
- Sometimes
- Frequently
- All the time

8. Self-confidence

Is your self-confidence reduced because of the vascular malformation?

- Not at all
- A little bit
- Moderately
- A lot
- Extremely

9. Satisfaction with the appearance of the vascular malformation

How satisfied are you with the appearance of the vascular malformation?

- Very satisfied
- Satisfied
- Not satisfied or dissatisfied
- Dissatisfied
- Very dissatisfied

CONCEPT

Satisfaction with treatment and outcomes scale

The following questions are about the outcomes of treatment (or the wait-and-see policy) of the vascular malformation. You only have to fill in the following questions if a treatment (or the wait-and-see policy) has already been started.

1. Size of the vascular malformation

How has the size of the vascular malformation changed since the start of treatment (or the wait-and-see policy)?

-4	-3	-2	-1	0	+1	+2	+3
Completely disappeared	Much smaller	Smaller	Slightly smaller	No change	Slightly larger	Larger	Much larger

I am unable to assess the size of the vascular malformation

2. Satisfaction with effect on general problems

How satisfied are you with the effect of the treatment (or the wait-and-see policy) on general problems because of the vascular malformation?

- Very satisfied
- Satisfied
- Not satisfied or dissatisfied
- Dissatisfied
- Very dissatisfied

3. Satisfaction with effect on pain

How satisfied are you with the effect of the treatment (or the wait-and-see policy) on the pain because of the vascular malformation?

- Very satisfied
- Satisfied
- Not satisfied or dissatisfied
- Dissatisfied
- Very dissatisfied
- I did not have pain because of the vascular malformation

4. Satisfaction with effect on the appearance

How satisfied are you with the effect of the treatment (or the wait-and-see policy) on the appearance of the vascular malformation?

- Very satisfied
- Satisfied
- Not satisfied or dissatisfied
- Dissatisfied
- Very dissatisfied
- I did not have appearance complaints because of the vascular malformation

5. Satisfaction with effect on physical functioning

How satisfied are you with the effect of the treatment (or the wait-and-see policy) on the functioning of your body? For example walking, moving the head, or moving the arms.

- Very satisfied
- Satisfied
- Not satisfied or dissatisfied
- Dissatisfied
- Very dissatisfied
- I did not have complaints of physical functioning because of the vascular malformation

6. Willingness to undergo treatment again

If you could choose again, would you choose the same treatment (or the same wait-and-see policy) you had?

- Yes
- No

If not, why not?

CONCEPT

Head and neck symptoms scale

The following questions are about possible head and neck symptoms of the vascular malformation. You only have to fill in the following questions if the vascular malformation affects the head and neck region.

1. Breathing problems because of the vascular malformation

In the past 4 weeks ...

I did not have this problem
(go to question 2)

I had this problem

↓

If you had this problem:

A. How much did this problem bother you?

- Not at all
- A little bit
- Moderately
- A lot
- Extremely

2. Eyesight problems because of the vascular malformation

In the past 4 weeks ...

I did not have this problem
(go to question 3)

I had this problem

↓

If you had this problem:

A. How much did this problem bother you?

- Not at all
- A little bit
- Moderately
- A lot
- Extremely

3. Hearing problems because of the vascular malformation

In the past 4 weeks ...

I did not have this problem
(go to question 4)

I had this problem

↓

If you had this problem:

A. How much did this problem bother you?

- Not at all
- A little bit
- Moderately
- A lot
- Extremely

4. Problems with swallowing because of the vascular malformation

In the past 4 weeks ...

I did not have this problem
(go to question 5)

I had this problem

↓

If you had this problem:

A. How much did this problem bother you?

- Not at all
- A little bit
- Moderately
- A lot
- Extremely

5. Speech problems because of the vascular malformation

In the past 4 weeks ...

I did not have this problem
(go to question 6)

I had this problem

↓

If you had this problem:

A. How much did this problem bother you?

- Not at all
- A little bit
- Moderately
- A lot
- Extremely

6. Problems with chewing because of the vascular malformation

In the past 4 weeks ...

I did not have this problem
(go to question 7)

I had this problem

↓

If you had this problem:

A. How much did this problem bother you?

- Not at all
- A little bit
- Moderately
- A lot
- Extremely

7. Problems with taste because of the vascular malformation

In the past 4 weeks ...

I did not have this problem
(go to question 8)

I had this problem

↓

If you had this problem:

A. How much did this problem bother you?

- Not at all
- A little bit
- Moderately
- A lot
- Extremely

8. Saliva leakage from the mouth because of the vascular malformation

In the past 4 weeks ...

I did not have this problem

I had this problem

↓

If you had this problem:

A. How much did this problem bother you?

- Not at all
- A little bit
- Moderately
- A lot
- Extremely