

Evaluation of the decision-making process of future parenthood when diagnosed with Turner syndrome

You recently visited the outpatient clinic for reproductive medicine at Radboudumc to discuss your diagnosis with Turner’s syndrome and the possibilities for future parenthood. With the support of a physician, you have made a choice whether or not to freeze ovarian tissue, or to wait with this decision a little longer. We would like you to share your experiences of this decision-making process with us. That is why we ask you to fill out this questionnaire (together with your parents).

1.1 What did you think of the general guidance you received during the decision-making process?

Especially contributing to existing care	Contributing to existing care	Neutral	Little contributing to existing care	Not contributing to existing care
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

1.2 Can you please elaborate?

2.1 How did you experience the different components during the decision-making process?

	Especially contributing to existing care	Contributing to existing care	Neutral	Little contributing to existing care	Not contributing to existing care
a) I thought the informative meeting was	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) I thought the decision aid on the Radboud website was	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) I thought the personal consultation with the physician was	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3.1 Which component was key when it came to making your final decision?

- The informative meeting
- The decision aid on the Radboud website
- The personal consultation

3.2 Can you please elaborate?

4.1 Did you consult any sources other than those mentioned above during the decision-making process?

- No
- Yes, namely...

5.1 Which choice did you make? Please select just one answer.

- To wait
- To pursue a future wish for children by way of adoption, foster care or egg donation
- To freeze egg cells by way of IVF treatment
- To freeze ovarian tissue for research purposes
- I have not made a choice (as yet)

6.1 Did you ever receive information about the Turner syndrome and (in)fertility before this counselling process?

- No
- Yes, namely...

7.1 Do you think fertility counselling is contributing to the existing care for a girl diagnosed with Turner syndrome?

- No
- Yes

7.2 Can you please elaborate?

8.1 How difficult was it for you to talk about this subject. Please select an answer below.

- | | | |
|----------------------------|-----------------------|-----------------------|
| Not
difficult at
all | Somewhat
difficult | Very
difficult |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

8.2 Can you please elaborate?

9.1 How did you find out that it was possible to have a counselling?

- Via my paediatrician
- Via TurnerContact Nederland
- Via the Radboudumc website
- Via a press release
- Via Social Media
- Otherwise, namely

To conclude, we would like to ask you a few more questions that may have possibly contributed to the selection process.

10.1 What is the composition of your family? (number of people, relationship to each other etc.)

10.2 Do you have any brothers or sisters?

- | | | | |
|---------------------------|------------------------|----------------------|---------------------------|
| <input type="radio"/> No | | | |
| <input type="radio"/> Yes | Number of
brothers: | <input type="text"/> | Age: <input type="text"/> |
| | Number of
sisters: | <input type="text"/> | Age: <input type="text"/> |

10.2.1 If the answer is yes, are they healthy or do they have a chronic illness?

10.3 Are you currently in a relationship?

- No
- Yes
- Does not apply

10.4 What is your father's highest level of education?

- Elementary school
- Preparatory secondary vocational education
- Higher general secondary education
- Secondary vocational education
- Higher professional education
- University education

10.5 What is your mother's highest level of education?

- Elementary school
- Preparatory secondary vocational education
- Higher general secondary education
- Secondary vocational education
- Higher professional education
- University education

10.6 Have your parents gone through fertility treatment?

- No
- Yes, namely...

11.1 Do you have any suggestions for improvement?

11.2 Would you like to add anything?

Please do not forget to enclose the consent form. Thank you for completing the questionnaire.