

## ***Appendix 1.***

### ***Survey patients***



Participation in this questionnaire is entirely voluntary. Your privacy will be respected. The study is completely anonymous.

#### **What is this research about?**

This study concerns making a choice for a gynaecological treatment.

#### **Who is this questionnaire for?**

The questionnaire is intended for women (18+) who have ever had an appointment with a gynaecologist.

#### **Completing the questionnaire**

Your answers can be ticked in the appropriate box. There is room for explanation for some questions.

#### **Handing in**

You can hand in the completed questionnaire at the counter of the gynaecological department.

Thanks for completing the questionnaire!

## General data

Age \_\_\_\_\_ years old

Level of education ☐ None ☐ Elementary ☐ VMBO ☐ HAVO  
☐ VWO ☐ MBO ☐ HBO  
☐ WO

Do you want children? ☐ No ☐ Yes

Have you ever been pregnant? ☐ No ☐ Yes, how often,? \_\_\_\_\_

Do you have children? ☐ No ☐ Yes, how many? \_\_\_\_\_

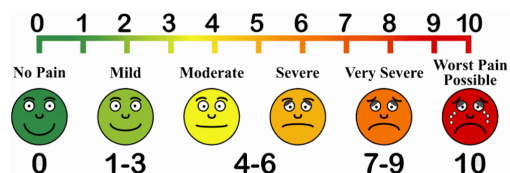
Are you sterilized? ☐ No ☐ Yes

Have you ever had a caesarean? ☐ No ☐ Yes, how many? \_\_\_\_\_

Are you still menstruating? ☐ Yes  
☐ No (due to contraceptives)  
☐ No (due to menopause)  
☐ No due to other reasons  
(hormonal/ removing endometrium/ removing uterus/adhesions)

How long is or was your period? \_\_\_\_\_ days

Do/did you have abdominal pain during you period? ☐ No ☐ Yes, how much? \_\_\_\_\_(0-10)



Do/did you have heavy flow during your period? ☐ No ☐ Yes ☐ Sometimes

When yes, how much flow on the worst day?

Use of tampons and/or sanitary pads a day: ☐ Less than 5 ☐ 5 or more

Have you ever heard of removing or burning away the endometrium?  
(endometrial ablation, such as Novasure, Thermablate, Thermachoice or Cavaterm)?

☐ No ☐ Yes

When yes: This information was: ☐ Positive ☐ Negative ☐ Neutral

Did you get endometrial ablation yourself? ☐ No ☐ Yes

Have you ever heard of removing the uterus entirely?

☐ No

☐ Yes

When yes:

This information was:

☐ Positive

☐ Negative

☐ Neutral

Did you get your uterus removed entirely?

☐ No

☐ Yes

When yes, reason:

☐ Prolapse

☐ Abdominal pain

☐ Heavy flow

☐ Cancer

☐ Other \_\_\_\_\_

I base my personal choice for medical treatment on:

☐ Someone else makes this decision for me

☐ Knowledge gathered from the internet/books/patient flyers

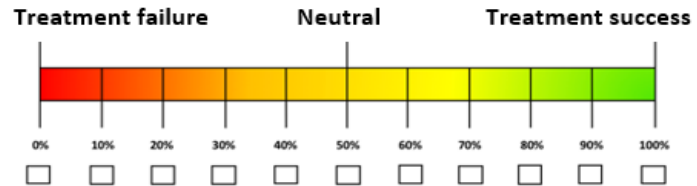
☐ Knowledge and experience of the doctor

☐ Experiences of people I know who had the same treatment

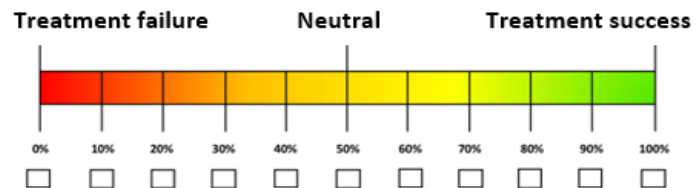
☐ Other: \_\_\_\_\_

What do you think the success rate (goal of operation retrieved, no reason for re-intervention) of operations mentioned below? (*tick the percentage*)

a. Removing of the infected appendix is according to me:



b. Repairing an inguinal hernia is according to me:



d. An endometrial ablation (removing endometrium) is according to me:

Try to imagine yourself in the following **imaginary case**:

You are a healthy 37-year-old woman, mother of a complete family with 2 children. One of the children was born by caesarean section. Your child wish has been completed.

For the past two years you have suffered from a lot of blood loss during your period. Every month again, (sometimes) for even 12 days! This puts you in an uncomfortable or clumsy situation several times. You also suffer from heavy pains during your period.

You have been satisfactorily examined by the gynaecologist and nothing abnormal has been found. Your gynaecologist discusses the treatment options for heavy blood loss. The pill and Mirena IUD appear not to be a suitable option for you.

Possible treatments are:

1. Endometrial ablation. A treatment to eliminate or reduce this heavy loss of blood. The endometrium is removed under local anaesthesia or during a light sedation at the outpatient clinic. After a short treatment of only 30 minutes, you can go home after 1 hour. Theoretically, this has a success rate of 85% (complete disappearance or reduction of vaginal blood loss). Although you remain fertile, pregnancy is not recommended because of the high risks for you and the unborn child, so you should take contraception.
  
2. Surgical removal of the entire uterus under general anaesthetics. This gives you an almost certain guarantee that the menstrual bleeding will disappear. After this operation, you will be hospitalized for 2 to 5 days. Unfortunately, this operation is not without risks (possible risks include thrombosis, bleeding, cystitis). Long-term consequences can include complaints of prolapse and change in sexual experience.

Which treatment do you choose?

☐ Removing endometrium (endometrial ablation)



Go to **A**

☐ Removing uterus entirely



Go to **B**

## A

You choose endometrial ablation (removing the endometrium).

### 1. On what motives did you make your choice?

	Strongly Disagree	Disagree	Neutral	Agree	Strongly agree
Outpatient procedure (no hospital admission)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Quick recovery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Less to no absenteeism	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Avoiding general anaesthetics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fewer risks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No permanent scar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Costs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other ...					

You have read on the internet that endometrial ablation does not work in 15% of women. To gain a better insight into a woman's individual chances, we have developed a mathematical prediction model that calculates this risk of failure. Your chance of endometrial ablation failure appears to be around 61%.

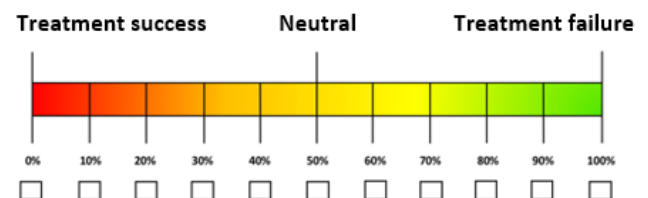
*(Failure = You continue to lose blood, you continue to have abdominal pain, you are dissatisfied with the treatment, you have to undergo another endometrial ablation or you eventually have to undergo a removal of the entire uterus to make the complaints disappear).*

2. Do you still choose endometrial ablation as treatment?

☐ Yes

☐ No

3. From what percentage of failure, would you no longer opt for endometrial ablation? If the failure rate is.... %. (tick the percentage)



You chose a percentage between 0% and 60%. Go to question 4.

You chose a percentage between 61% and 100%. Go to question 5.

4. You have chosen a percentage between 0% and 60%. Why did you chose this specific percentage? *(multiple options possible)*

☐ Because the risk of failure is too high.

☐ Because I think removing the uterus entirely is a better solution.

☐ Other: \_\_\_\_\_

5. You have chosen a percentage between 61% and 100%. Why did you chose this specific percentage? *(multiple options possible)*

☐ Because I can avoid possible higher risks of a larger operation (such as removing the uterus entirely)

☐ Because it is worth trying this first, taking pros to cons in consideration.

☐ I want to keep my uterus

☐ Other: \_\_\_\_\_

## B

You chose removing the uterus entirely.

1. On what motives did you make your choice?

	Strongly Disagree	Disagree	Neutral	Agree	Strongly agree
No longer contraceptives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No more periods	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No more pain during period	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General anaesthetics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
One-off treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Uterus became unnecessary	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Costs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other ...					



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*(Failure = You continue to lose blood, you continue to have abdominal pain, you are dissatisfied with the treatment, you have to undergo another endometrial ablation or you eventually have to undergo a removal of the entire uterus to make the complaints disappear).*

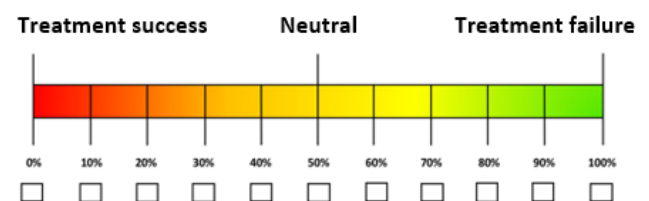
2. Do you still choose removing the uterus entirely as treatment?

☐ Yes

☐ No

3. From what percentage of failure, would you no longer opt for endometrial ablation?

If the failure rate is.... %. (tick the percentage)



You chose a percentage between 0% and 60%. Go to question 4.

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☐ Other: \_\_\_\_\_

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☐ Because I can avoid possible higher risks of a larger operation (such as removing the uterus entirely)

☐ Because it is worth trying this first, taking pros to cons in consideration.

☐ I want to keep my uterus.

☐ Other: \_\_\_\_\_

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This was the end of this questionnaire. The entire research team wants to thank you for your participation. You can hand in the questionnaire at the desk.