

## Report from ‘COSAR Delphi round 2’

Collected results per. 4. November 2021 23:59

- Delivered replies: **291**
- Commenced replies: **0**
- Number of sent invitations: **0**

### Without text answers



### Welcome to COSAR round 2!

It takes about 6-10 minutes to do this survey.

On the next page, we present a list of outcomes of adenomyosis treatment.

Any of these outcomes may or may not be relevant to you personally. However, please tell us on the scale below how important you think it is that future studies on adenomyosis treatments report these outcomes.

If you want to read more about outcomes in adenomyosis research, please visit our [COSAR website](#).

**Thank you for participating in this important work.**

### To which stakeholder group do you belong? \*

Please choose in which capacity you are participating in this survey. Only one answer is possible.

Answer	Number of	Percentage
Person with adenomyosis	181	<b>62.2%</b>
Partner of person with adenomyosis	2	<b>0.7%</b>
Health care professional	93	<b>32%</b>
Researcher	15	<b>5.2%</b>

### We will now present the outcomes from Round 1 and new outcomes:

- The list of outcomes that reached the predefined level of agreement: *they are included*
- The outcomes that did **not** reach agreement: *we ask you to vote again*
- New outcomes that were suggested by the participants: *please vote*

Any of these outcomes may or may not be relevant to you personally. However, please tell us on the scale below how important you think it is that all future studies on adenomyosis treatment reports these outcomes.

### Category 1: Pain

The following outcomes reached **agreement** in the first round to be **included** in the core outcome set:

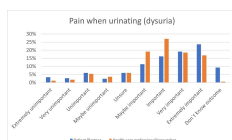
- Cyclic pelvic pain (*includes pain during ovulation*)
- Pain during toilet visit (*dyschezia*)
- Painful periods (*dysmenorrhoea*)
- Pain during sex (*dyspareunia*)
- Pelvic pain that comes without a trigger (*non-cyclic, unprovoked pain*)

### Outcomes that have not reached agreement:

Below you will be asked to vote again on three pain associated outcomes. The average results from the last round are displayed to help you to decide.

### Pain when urinating (dysuria)

The graph shows how participants categorized this outcome in the first round.



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in **all** future studies on adenomyosis.

### Response distribution (raw data)

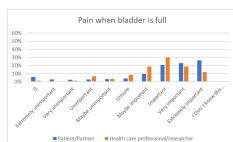
	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know this outcome
Pain when urinating (Dysuria) *	12	4	25	16	21	36	83	50	36	8

**Response distribution (%)**

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know this outcome
Pain when urinating (Dysuria) *	4.1%	1.4%	8.6%	5.5%	7.2%	12.4%	28.5%	17.2%	12.4%	2.7

**Pain when bladder is full**

The graph shows how participants categorized this outcome in the first round.



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in **all** future studies on adenomyosis.

**Response distribution (raw data)**

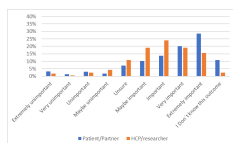
	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I don't know this outcome
Pain when bladder is full *	7	7	18	18	14	48	76	51	47	5

**Response distribution (%)**

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I don't know this outcome
Pain when bladder is full *	2.4%	2.4%	6.2%	6.2%	4.8%	16.5%	26.1%	17.5%	16.2%	1.7%

**Pain associated vomiting**

The graph shows how participants categorized this outcome in the first round.



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in **all** future studies on adenomyosis.

**Response distribution (raw data)**

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know this outcome
Pain	15	10	27	14	33	41	64	41	30	16

associated vomiting *										
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**Response distribution (%)**

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know this outcome
Pain associated vomiting *	5.2%	3.4%	9.3%	4.8%	11.3%	14.1%	22%	14.1%	10.3%	5.5

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**New outcomes that were suggested in Round 1**

Please indicate, in your opinion, how important it is that the outcome will be measured and reported in **all** future studies on adenomyosis.

**Response distribution (raw data)**

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)
Radiating pain to legs/leg pain *	5	1	13	11	14	49	68	59	68
Feeling pressure in pelvic area/lower part of the belly (bulk symptoms) *	5	2	3	7	4	24	67	74	104
Bloating/trapped gas *	7	5	18	8	14	48	67	49	72

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**Response distribution (%)**

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)
Radiating pain to legs/leg pain *	1.7%	0.3%	4.5%	3.8%	4.8%	16.8%	23.4%	20.3%	23.4%
Feeling pressure in pelvic area/lower part of the belly (bulk symptoms) *	1.7%	0.7%	1%	2.4%	1.4%	8.2%	23%	25.4%	35.7%
Bloating/trapped gas *	2.4%	1.7%	6.2%	2.7%	4.8%	16.5%	23%	16.8%	24.7%

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**Category 2: Urinary symptoms and findings**

The following outcomes reached agreement in the first round to be included in the core outcome set:

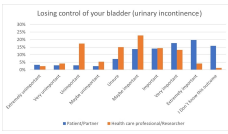
- Needing to urinate often (*Urinary frequency*)

**Outcomes that have not reached agreement:**

Below you will be asked to vote again on two old and two new outcomes in this category. The average results from the last round are displayed to help you to decide.

**Losing control of your bladder (urinary incontinence)**

The graph shows how participants categorized this outcome in the first round:



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in **all** future studies on adenomyosis.

**Response distribution (raw data)**

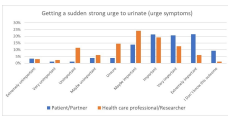
	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	
Losing control of your bladder (urinary incontinence) *	11	5	42	19	26	52	54	32	40	

**Response distribution (%)**

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	
Losing control of your bladder (urinary incontinence) *	3.8%	1.7%	14.4%	6.5%	8.9%	17.9%	18.6%	11%	13.7%	

**Getting a sudden strong urge to urinate (Urge symptoms)**

The graph shows how participants categorized this outcome in the first round:



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in **all** future studies on adenomyosis.

**Response distribution (raw data)**

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know this outcome
Getting a sudden strong urge to urinate (Urinary urgency) *	8	4	29	9	15	54	74	56	38	4

**Response distribution (%)**

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know this outcome
Getting a sudden strong urge to urinate (Urinary urgency) *	2.7%	1.4%	10%	3.1%	5.2%	18.6%	25.4%	19.2%	13.1%	1.4%

**New outcome(s) that were suggested in Round 1**

### Incomplete bladder emptying (residual urine)

Please indicate, in your opinion, how important it is that the outcome will be measured and reported in **all** future studies on adenomyosis.

#### Response distribution (raw data)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know
Incomplete bladder emptying (residual urine) *	5	3	27	20	16	50	75	45	43	7

#### Response distribution (%)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know
Incomplete bladder emptying (residual urine) *	1.7%	1%	9.3%	6.9%	5.5%	17.2%	25.8%	15.5%	14.8%	2.4%

### Category 3: Abnormal uterine bleeding and menstruation

The following outcomes reached **agreement** in the first round to be included in the core outcome set:

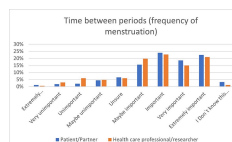
- How heavy the menstrual bleeding is (*menstrual blood flow volume*)
- How long the period lasts (*duration of bleeding*)
- Bleeding between periods (*intermenstrual bleeding*)

#### Outcomes that have not reached agreement:

Below you will be asked to vote again on four outcomes in this category. The average results from the last round are displayed to help you to decide.

#### Time between periods (frequency of menstruation)

The graph shows how participants categorized this outcome in the first round:



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in all future studies on adenomyosis.

#### Response distribution (raw data)

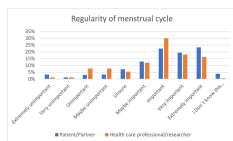
	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know
Time between periods (Frequency of menstruation) *	1	3	17	11	17	39	76	67	52	

#### Response distribution (%)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know
Time between periods (Frequency of menstruation) *	0.3%	1%	5.8%	3.8%	5.8%	13.4%	26.1%	23%	17.9%	

### Regularity of menstrual cycle (irregular periods)

The graph shows how participants categorized this outcome in the first round:



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in all future studies on adenomyosis.

#### Response distribution (raw data)

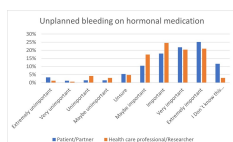
	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know this outcome
Regularity of menstrual cycle (Irregular periods) *	4	4	19	12	16	39	84	62	43	8

#### Response distribution (%)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know this outcome
Regularity of menstrual cycle (Irregular periods) *	1.4%	1.4%	6.5%	4.1%	5.5%	13.4%	28.9%	21.3%	14.8%	2.7%

### Unplanned bleeding on hormonal medication

The graph shows how participants categorized this outcome in the first round:



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in all future studies on adenomyosis.

#### Response distribution (raw data)

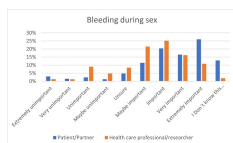
	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know this outcome
Unplanned bleeding on hormonal medication *	3	2	9	7	7	34	77	67	73	4

#### Response distribution (%)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know this outcome
Unplanned bleeding on hormonal medication *	1%	0.7%	3.1%	2.4%	2.4%	11.7%	26.5%	23%	25.1%	4%

### Bleeding during sex

The graph shows how participants categorized this outcome in the first round:



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in all future studies on adenomyosis.

#### Response distribution (raw data)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I don't know this outcome
Bleeding during sex *	4	5	8	10	13	41	84	61	53	12

#### Response distribution (%)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I don't know this outcome
Bleeding during sex *	1.4%	1.7%	2.7%	3.4%	4.5%	14.1%	28.9%	21%	18.2%	4.1%

### Category 4: Fertility, pregnancy and childbirth

The following outcomes reached **agreement** amongst the participants.

- Pregnancy with a heartbeat (*Viable intrauterine pregnancy, ultrasound confirmed*)
- Number of embryos (single, twins, or more)
- Live birth
- At how many weeks of pregnancy the baby is born (*Gestational age at delivery*)
- Birthweight
- Death of baby before, during or shortly after birth (*Neonatal mortality*)
- Genetic disorder the baby is born with (*Major congenital anomaly*)
- Time to pregnancy leading to live birth
- Early pregnancy loss (*Miscarriage*)
- Mode of conception (*was fertility treatment needed to become pregnant*)
- Heavy bleeding during and after the delivery (*peri/postpartum hemorrhage*)

Not all women that participate in adenomyosis studies still wish to have children, and the following outcomes might not be relevant for all studies.

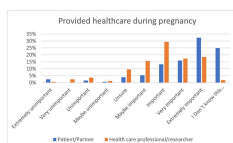
Please indicate, in your opinion, how important it is that the outcome will be measured and reported in all future studies that investigate fertility issues in women treated for adenomyosis.

#### Outcomes that have not reached agreement:

Below you will be asked to vote again on outcomes in this category. The average results from the last round are displayed to help you to decide.

### Provided healthcare during pregnancy

The graph shows how participants categorized this outcome in the first round:



This outcome describes for example how often the pregnant person had checkups.

Please indicate, in your opinion, how important it is that the outcome will be measured and reported in all future studies on adenomyosis that look into obstetrical outcomes after adenomyosis treatment.

**Response distribution (raw data)**

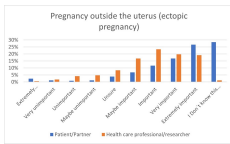
	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know (10)
Healthcare during pregnancy (Antenatal care) *	7	1	11	7	21	19	65	54	79	2

**Response distribution (%)**

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know (10)
Healthcare during pregnancy (Antenatal care) *	2.4%	0.3%	3.8%	2.4%	7.2%	6.5%	22.3%	18.6%	27.1%	9.3

**A pregnancy located outside the uterus (ectopic pregnancy)**

The graph shows how participants categorized this outcome in the first round:



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in all future studies on adenomyosis.

**Response distribution (raw data)**

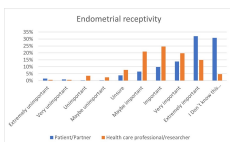
	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know (10)
A pregnancy located outside the uterus (ectopic pregnancy) *	4	3	8	3	10	30	68	67	67	

**Response distribution (%)**

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know (10)
A pregnancy located outside the uterus (ectopic pregnancy) *	1.4%	1%	2.7%	1%	3.4%	10.3%	23.4%	23%	23%	10

**Molecular markers of reproductive function of the lining of the uterus (endometrial receptivity)**

The graph shows how participants categorized this outcome in the first round:





Please indicate, in your opinion, how important it is that the outcome will be measured and reported in all future studies on adenomyosis.

### Response distribution (raw data)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I don't know this outcome
Molecular markers of reproductive function of the lining of the uterus (Markers of endometrial receptivity) *	4	3	6	3	14	31	66	53	77	

### Response distribution (%)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I don't know this outcome
Molecular markers of reproductive function of the lining of the uterus (Markers of endometrial receptivity) *	1.4%	1%	2.1%	1%	4.8%	10.7%	22.7%	18.2%	26.5%	11

### How the baby was born (mode of delivery)

The graph shows how participants categorized this outcome in the first round:



This outcome describes if a baby was born with a Cesarean section or natural delivery.

Please indicate, in your opinion, how important it is that the outcome will be measured and reported in all future studies on adenomyosis looking into obstetrical outcomes after adenomyosis treatment.

### Response distribution (raw data)

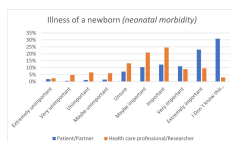
	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I don't know this outcome
Mode of delivery (How the baby was born) *	7	1	13	9	23	34	90	35	44	35

### Response distribution (%)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I don't know this outcome
Mode of delivery (How the baby was born) *	2.4%	0.3%	4.5%	3.1%	7.9%	11.7%	30.9%	12%	15.1%	12%

### Illness of a newborn (Neonatal morbidity)

The graph shows how participants categorized this outcome in the first round:



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in all future studies on adenomyosis.

#### Response distribution (raw data)

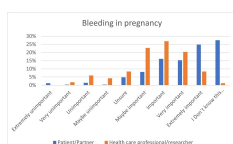
	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	Did not know the outcome
Illness of a newborn (Neonatal morbidity) *	4	1	16	10	31	44	53	42	54	3

#### Response distribution (%)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	Did not know the outcome
Illness of a newborn (Neonatal morbidity) *	1.4%	0.3%	5.5%	3.4%	10.7%	15.1%	18.2%	14.4%	18.6%	12.1%

### Bleeding in pregnancy

The graph shows how participants categorized this outcome in the first round:



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in all future studies on adenomyosis.

#### Response distribution (raw data)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	Did not know the outcome
Bleeding in pregnancy *	4	2	3	9	13	33	71	66	59	10

#### Response distribution (%)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	Did not know the outcome
Bleeding in pregnancy *	1.4%	0.7%	1%	3.1%	4.5%	11.3%	24.4%	22.7%	20.3%	10.3%

## New outcome(s) that were suggested in Round 1

### Placental complications (Malplacentation)

This outcome describes if the placenta is implanted in the wrong place or grown too deep into the wall of the uterus. Medical terms for this include placenta accreta, increta, percreta, previa and so on.

Please indicate, in your opinion, how important it is that the outcome will be measured and reported in all future studies on adenomyosis.

#### Response distribution (raw data)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)
Placental complications/disorders *	1	2	4	4	10	24	76	60	71

#### Response distribution (%)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)
Placental complications/disorders *	0.3%	0.7%	1.4%	1.4%	3.4%	8.2%	26.1%	20.6%	26.1%

## Category 5: Hematology and laboratory findings

The following outcomes reached **agreement** in the first round to be included in the core outcome set:

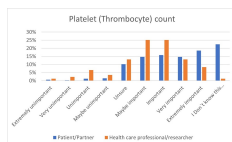
- Hemoglobin
- Ferritin (iron levels)

### Outcomes that have not reached agreement:

Below you will be asked to vote again on the four outcomes that did not reach agreement. The average results from the last round are displayed to help you to decide.

### Platelet count (Thrombocytes)

The graph shows how participants categorized this outcome in the first round:



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in all future studies on adenomyosis.

#### Response distribution (raw data)

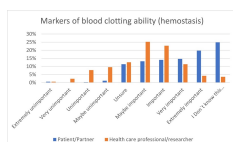
	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)
Platelet (Thrombocyte) count *	3	3	12	13	49	54	63	29	27

#### Response distribution (%)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)
Platelet (Thrombocyte) count *	1%	1%	4.1%	4.5%	16.8%	18.6%	21.6%	10%	9.3%

### Genetic and molecular markers of blood clotting ability (Hemostasis)

The graph shows how participants categorized this outcome in the first round:



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in all future studies on adenomyosis.

#### Response distribution (raw data)

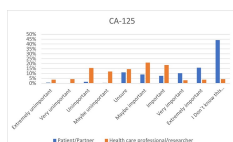
	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	
Genetic and molecular markers of blood clotting ability (hemostasis) *	5	2	14	16	37	47	72	35	32	

#### Response distribution (%)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	
Genetic and molecular markers of blood clotting ability (hemostasis) *	1.7%	0.7%	4.8%	5.5%	12.7%	16.2%	24.7%	12%	11%	

### CA-125

The graph shows how participants categorized this outcome in the first round:



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in all future studies on adenomyosis.

#### Response distribution (raw data)

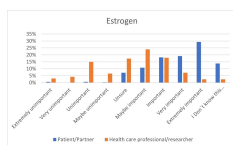
	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I don't know this outcome
CA-125 *	9	3	30	26	34	48	40	17	28	56

#### Response distribution (%)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I don't know this outcome
CA-125 *	3.1%	1%	10.3%	8.9%	11.7%	16.5%	13.7%	5.8%	9.6%	19.2%

### Estrogen levels

The graph shows how participants categorized this outcome in the first round:



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in all future studies on adenomyosis.

#### Response distribution (raw data)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I don't know this outcome
Estrogen levels*	7	3	25	12	27	46	64	45	51	11

#### Response distribution (%)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I don't know this outcome
Estrogen levels*	2.4%	1%	8.6%	4.1%	9.3%	15.8%	22%	15.5%	17.5%	3.8%

### Category 6: Life impact

There was agreement that these outcomes should be included in a future core outcome set:

- Health-related Quality of life
- Sexual functioning Health-related quality of life (HRQoL) is a concept that looks at how disease influences a person’s physical, mental, emotional, and social functioning. For example how pain influences how active we can be or if it makes us depressed.

There were no new suggestions in this category, that were not already covered in the accepted outcomes.

### Category 7: Delivery of care (outcomes related to the treatment itself)

The following outcomes reached **agreement** in the first round to be included in the core outcome set:

- Patient compliance (*How well a patient follows a treatment*)
- Patient satisfaction with treatment
- Discomfort/pain during procedure
- Recovery time after procedure
- How much better the worst symptom gets (*Symptom relief rate*)
- How long it takes for the worst symptom to come back (*Time to symptom recurrence for most bothersome symptom*)
- How long it takes for all symptoms to come back (*Time to symptom recurrence for any symptom*)
- Size of adenomyosis lesion (*Lesion size*)
- Size/volume of uterus

#### Outcomes that have not reached agreement:

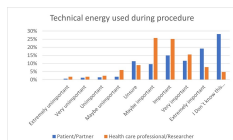
Below you will be asked to vote again on outcomes that could be looked at when doing procedures.

Some outcomes may only apply to studies that do surgery or other types of interventions. If voted to be critical, those outcomes will only be measured and reported where applicable.

The average results from the last round are displayed to help you to decide.

### Technical energy used during a procedure

The graph shows how participants categorized this outcome in the first round.



"Technical energy" applies to certain procedures where energy is used to destroy adenomyosis tissue (for example, thermal ablation or high intensity focused ultrasound). It does *not* describe the effort a physician has to put in performance of a procedure.

Please indicate, in your opinion, how important it is that the outcome will be measured and reported in future studies on adenomyosis.

**Response distribution (raw data)**

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know
Technical energy used during procedure *	3	3	10	13	29	34	76	54	33	3

**Response distribution (%)**

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know
Technical energy used during procedure *	1%	1%	3.4%	4.5%	10%	11.7%	26.1%	18.6%	11.3%	12%

**Time it takes to perform a procedure**

The graph shows how participants categorized this outcome in the first round:



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in future studies on adenomyosis.

**Response distribution (raw data)**

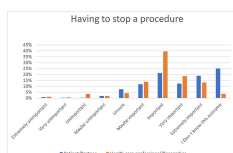
	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know
Time it takes to perform a procedure (Procedure time) *	5	4	11	8	22	46	114	35	27	1

**Response distribution (%)**

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I do not know
Time it takes to perform a procedure (Procedure time) *	1.7%	1.4%	3.8%	2.7%	7.6%	15.8%	39.2%	12%	9.3%	6.5%

**Having to stop a procedure before it was finished (Premature termination of procedure)**

The graph shows how participants categorized this outcome in the first round:



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in future studies on adenomyosis.

### Response distribution (raw data)

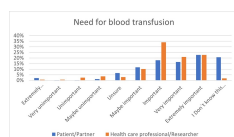
	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	Impact
Having to stop a procedure before it was finished (Premature termination of procedure) *	3	0	4	4	15	34	111	52	43	

### Response distribution (%)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	Impact
Having to stop a procedure before it was finished (Premature termination of procedure) *	1%	0%	1.4%	1.4%	5.2%	11.7%	38.1%	17.9%	14.8%	8

### Need for blood transfusion

The graph shows how participants categorized this outcome in the first round:



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in future studies on adenomyosis.

### Response distribution (raw data)

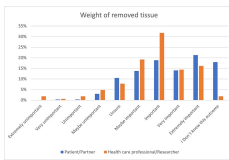
	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	Impact
Need for blood transfusion *	3	4	4	5	15	28	88	65	54	

### Response distribution (%)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	Impact
Need for blood transfusion *	1%	1.4%	1.4%	1.7%	5.2%	9.6%	30.2%	22.3%	18.6%	8

### Weight of removed tissue

The graph shows how participants categorized this outcome in the first round:



Please indicate, in your opinion, how important it is that the outcome will be measured and reported in future studies on adenomyosis.

#### Response distribution (raw data)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I don't know this outcome
Weight of removed tissue*	8	2	11	5	22	52	84	55	31	21

#### Response distribution (%)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I don't know this outcome
Weight of removed tissue*	2.7%	0.7%	3.8%	1.7%	7.6%	17.9%	28.9%	18.9%	10.7%	7.2%

### Category 8: Economy

In this category, we asked to rate outcomes that are related to costs associated with the treatment. There were no undecided outcomes.

The following outcomes reached agreement in the first round to be included in the core outcome set:

- Costs of treatment
- How much the patient has to pay for a treatment (*Patient costs*)
- Value-for-money of treatment (*Cost-utility analysis*)
- Need for repeated or other treatment (*Need for re-intervention*)
- Length of hospital stay

### Category 9: Adverse outcomes

In this category, we asked you to rate outcomes related to harms caused by a treatment. There were no undecided outcomes.

The following outcomes reached agreement in the first round to be included in the core outcome set:

- Death
- Infections
- All harms, injuries and toxic reactions occurring

### Category 10: Reporting Items

There was agreement that researchers need to report the following things, when describing the people participating in a study:

- If endometriosis was present or not
- If fibroids (myoma) were present or not
- If the person wished to become pregnant in the future
- What treatment(s) of adenomyosis had been tried before
- Description of adenomyosis with using classification

### New reporting item

#### Chronic pelvic pain

Chronic pelvic pain is pain in the pelvic area (low in the belly) that lasts for 6 months or longer. Chronic pain can come and go, or it can be constant. Chronic pelvic pain can follow a regular cycle or not.

Please rate how important it is that it is reported if a person participating in a study on adenomyosis has chronic pelvic pain.

#### Response distribution (raw data)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I don't know this outcome



Presence of chronic pelvic pain *	4	1	0	0	1	5	48	75	157	0
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Response distribution (%)

	Extremely unimportant (1)	Very unimportant (2)	Unimportant (3)	Maybe unimportant (4)	Unsure unimportant or important (5)	Maybe important (6)	Important (7)	Very important (8)	Extremely important (9)	I don't know this outcome
Presence of chronic pelvic pain *	1.4%	0.3%	0%	0%	0.3%	1.7%	16.5%	25.8%	54%	0%

Thank you so much for your participation!



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