Report from 'COSAR'

Collected results per. 30. July 2021 13:24

- Delivered replies: **501**
- Commenced replies: **0**
- Number of sent invitations: **0**

Without text answers

Welcome to COSAR!

In this survey, we are interested in your OPINION on what outcomes should be measured and reported in all future studies investigating the treatment of adenomyosis.

An outcome describes something that is measured, for example pain or satisfaction.

To have outcomes that are carefully chosen by researchers, doctors and patients is extremely important. This will ensure the quality of research and by that, the quality of patient care.

If you want to read more about outcomes in adenomyosis research, please visit our COSAR website.

Thank you for participating in this important work.

It takes about 8-20 minutes to do this survey.

The process of outcome selection is done in several steps. This is the first of two rounds of voting.

You can participate if:

- you have adenomyosis or if you are a partner of a person with adenomyosis
- You are a healthcare professional treating people with adenomyosis
- If you are a researcher in the field of adenomyosis

The survey is anonymous and your answers will not be linked to you personally.

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	327	**65.3%**	
Partner of person with adenomyosis	7	**1.4%**	
Health care professional	150	**29.9%**	
Researcher	17	**3.4%**	

To which category of health care professional do you belong? *

Please choose from the menu.

Answer	Number of	Percentage	
Chiropractor/osteopath	2	**1.3%**	
Doctor	141	**94%**	
Midwife	2	**1.3%**	
Nurse	3	**2%**	
Physiotherapist	2	**1.3%**	
Psychotherapist	0	**0%**	

We will now present various outcomes in ten different categories. The outcomes are sorted alphabetically or thematically.

Please rate how important you find it that this outcome should be measured in all future studies on adenomyosis.

You can rate each outcome from 1-9, with increasing importance:
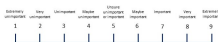
If you do not know an outcome and feel unable to rate it, you can check "**I don't know this outcome**".

At the end of each category, you can leave a comment or suggest other outcomes for that category.

In this step of the process, we are not asking you to discuss how and with what tools outcomes should be measured.
We will ask you for example if you think that "heavy bleeding during period" should be measured in studies, but not how you think bleeding is best measured.

Category 1: Pain

In this first category, we ask you to rate outcomes related to "Pain".

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

If you are not familiar with an outcome, please choose "I don't know this outcome".

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)
Cyclical pelvic pain (pain coming at the same time in the menstrual cycle) *	10	5	0	1	4	11	56	118	292
Pain during toilet visit when opening bowels (Dyschezia) *	6	6	10	8	24	58	93	132	141
Pain when urinating (Dysuria) *	13	12	29	14	30	70	99	95	107
Pain when urinary bladder is full *	9	10	20	16	27	63	119	107	108
Painful periods (Dysmenorrhea) *	10	2	1	1	5	8	33	102	331
Pain during sex (Dyspareunia) *	7	7	5	1	6	40	60	127	231
Pelvic pain occuring without a trigger (non-cyclic, unprovoked pain) *	6	6	11	5	10	53	87	121	194
Pain-associated vomiting or fainting (losing consciousness) episodes *	14	6	14	13	42	66	86	99	121

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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)
Cyclical pelvic pain (pain coming at the same time in the menstrual cycle) *	2%	1%	0%	0.2%	0.8%	2.2%	11.2%	23.6%	58.3%
Pain during toilet visit when opening bowels (Dyschezia) *	1.2%	1.2%	2%	1.6%	4.8%	11.6%	18.6%	26.3%	28.1%
Pain when urinating (Dysuria) *	2.6%	2.4%	5.8%	2.8%	6%	14%	19.8%	19%	21.4%
Pain when urinary bladder is full *	1.8%	2%	4%	3.2%	5.4%	12.6%	23.8%	21.4%	21.6%
Painful periods (Dysmenorrhea) *	2%	0.4%	0.2%	0.2%	1%	1.6%	6.6%	20.4%	66.1%
Pain during sex (Dyspareunia) *	1.4%	1.4%	1%	0.2%	1.2%	8%	12%	25.3%	46.1%
Pelvic pain occuring without a trigger (non-cyclic, unprovoked pain) *	1.2%	1.2%	2.2%	1%	2%	10.6%	17.4%	24.2%	38.7%
Pain-associated vomiting or fainting (losing consciousness) episodes *	2.8%	1.2%	2.8%	2.6%	8.4%	13.2%	17.2%	19.8%	24.2%

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Category 2: Urinary symptoms and findings

In this category, we ask you to rate outcomes related to urinary symptoms and findings.

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

If you are not familiar with an outcome, please choose "I don't know this outcome".

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)	
Needing to urinate often (Urinary frequency) *	10	4	19	15	34	78	117	113	88	
Losing control of your bladder (Urinary incontinence) *	15	17	39	17	49	84	71	81	73	
Getting a sudden strong urge to urinate (Urinary urgency) *	16	8	23	23	37	86	103	90	82	

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)	
Needing to urinate often (Urinary frequency) *	2%	0.8%	3.8%	3%	6.8%	15.6%	23.4%	22.6%	17.6%	
Losing control of your bladder (Urinary incontinence) *	3%	3.4%	7.8%	3.4%	9.8%	16.8%	14.2%	16.2%	14.6%	
Getting a sudden strong urge to urinate (Urinary urgency) *	3.2%	1.6%	4.6%	4.6%	7.4%	17.2%	20.6%	18%	16.4%	

Category 3: Abnormal uterine bleeding and menstruation

In this category, we ask you to rate outcomes related to abnormal uterine bleeding.

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

If you are not familiar with an outcome, please choose "I don't know this outcome".

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)	
How heavy the menstrual bleeding is (Menstrual blood flow volume) *	6	7	1	4	6	19	70	121	257	
How many days the menstrual bleeding/period lasts (Duration of bleeding) *	8	4	6	5	15	36	112	130	174	
Time between periods	5	11	17	23	32	85	118	87	110	

(Frequency of menstruation) *									
Bleeding in between periods (Intermenstrual bleeding) *	12	7	16	17	35	57	110	102	119
Regularity of menstrual cycle (Irregular periods) *	13	6	23	24	33	63	125	95	105
Unplanned bleeding on hormone medication *	13	5	12	10	26	64	101	107	119
Bleeding during sex *	12	7	23	12	30	74	110	82	105

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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)	
How heavy the menstrual bleeding is (Menstrual blood flow volume) *	1.2%	1.4%	0.2%	0.8%	1.2%	3.8%	14%	24.2%	51.3%	
How many days the menstrual bleeding/period lasts (Duration of bleeding) *	1.6%	0.8%	1.2%	1%	3%	7.2%	22.4%	25.9%	34.7%	
Time between periods (Frequency of menstruation) *	1%	2.2%	3.4%	4.6%	6.4%	17%	23.6%	17.4%	22%	
Bleeding in between periods (Intermenstrual bleeding) *	2.4%	1.4%	3.2%	3.4%	7%	11.4%	22%	20.4%	23.8%	
Regularity of menstrual cycle (Irregular periods) *	2.6%	1.2%	4.6%	4.8%	6.6%	12.6%	25%	19%	21%	
Unplanned bleeding on hormone medication *	2.6%	1%	2.4%	2%	5.2%	12.8%	20.2%	21.4%	23.8%	
Bleeding during sex *	2.4%	1.4%	4.6%	2.4%	6%	14.8%	22%	16.4%	21%	

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Category 4: Fertility and obstetric outcomes

In this category, we ask you to rate outcomes related to fertility, pregnancy and childbirth.

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.

There is already a core outcome set for fertility research.

This outcome set was developed by researchers, doctors and infertile couples the same way we work with COSAR.

The infertility core outcome set contains the following outcomes:

1. Viable intrauterine pregnancy, ultrasound confirmed. 2. Reporting singleton pregnancy, twin pregnancy, higher multiple pregnancies, 3. Live birth, 4. Gestational age at delivery, 5. Birthweight, 6. Neonatal mortality, 7. Major congenital anomaly, 8. Time to pregnancy leading to live birth

*

*(**Lay terms:** 1. Pregnancy with a heartbeat, confirmed by ultrasound, 2. Number of embryos (single, twins, or more), 3. Live birth, 4. At how many weeks of pregnancy the baby is born, 5. Birthweight, 6. Death of baby before, during or shortly after birth, 7. Genetic disorder the baby is born with, 8. Time to pregnancy leading to live birth)*

We suggest adopting this existing core outcome set for studies that look into how the treatment of adenomyosis improves fertility.

Please rate how important you find it to report fertility outcomes.

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 know this outco
Fertility core outcome set (as described above) *	10	3	5	0	11	16	78	106	204	68

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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 know this outco
Fertility core outcome set (as described above) *	2%	0.6%	1%	0%	2.2%	3.2%	15.6%	21.2%	40.7%	13.6

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Other outcomes related to fertility, pregnancy and childbirth

Please rate the outcomes below and how important they are in your opinion.

If you are not familiar with an outcome, please choose "I don't know this outcome".

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)
Healthcare during pregnancy (Antenatal care) *	9	4	11	4	29	44	93	82	139
A pregnancy located outside the uterus (Ectopic pregnancy) *	9	7	10	12	27	51	78	89	121
Early pregnancy loss (Miscarriage) *	9	4	6	0	17	23	82	112	179
Molecular markers of reproductive function of the lining of the uterus (Markers of endometrial receptivity) *	6	4	7	5	26	57	74	79	132
Mode of conception (Was fertility treatment needed to become pregnant) *	6	5	3	5	12	42	92	98	164
Mode of delivery (How the baby was born) *	7	7	11	14	47	85	94	58	88
Illness of a newborn (Neonatal morbidity) *	10	10	15	15	46	70	82	52	93
Heavy bleeding during and after the delivery (Peri/postpartum hemorrhage) *	3	5	8	6	23	49	82	110	122

Bleeding in pregnancy *	4	4	15	8	30	65	99	85	97

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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)
Healthcare during pregnancy (Antenatal care) *	1.8%	0.8%	2.2%	0.8%	5.8%	8.8%	18.6%	16.4%	27.7%
A pregnancy located outside the uterus (Ectopic pregnancy) *	1.8%	1.4%	2%	2.4%	5.4%	10.2%	15.6%	17.8%	24.2%
Early pregnancy loss (Miscarriage) *	1.8%	0.8%	1.2%	0%	3.4%	4.6%	16.4%	22.4%	35.7%
Molecular markers of reproductive function of the lining of the uterus (Markers of endometrial receptivity) *	1.2%	0.8%	1.4%	1%	5.2%	11.4%	14.8%	15.8%	26.3%
Mode of conception (Was fertility treatment needed to become pregnant) *	1.2%	1%	0.6%	1%	2.4%	8.4%	18.4%	19.6%	32.7%
Mode of delivery (How the baby was born) *	1.4%	1.4%	2.2%	2.8%	9.4%	17%	18.8%	11.6%	17.6%
Illness of a newborn (Neonatal morbidity) *	2%	2%	3%	3%	9.2%	14%	16.4%	10.4%	18.6%
Heavy bleeding during and after the delivery (Peri/postpartum hemorrhage) *	0.6%	1%	1.6%	1.2%	4.6%	9.8%	16.4%	22%	24.4%
Bleeding in pregnancy *	0.8%	0.8%	3%	1.6%	6%	13%	19.8%	17%	19.4%

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Category 5: Hematology and laboratory findings

In this first category, we ask you to rate outcomes related to blood tests

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

If you are not familiar with an outcome, please choose "I don't know this outcome".

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)	
Iron levels (Ferritin) *	4	5	7	4	32	59	120	110	127	
Blood levels (Hemoglobin) *	5	1	6	9	27	57	112	111	128	
Platelet (Thrombocyte) count *	4	5	15	11	56	91	95	71	76	
Genetic and molecular markers of blood clotting	3	4	14	20	59	86	85	68	73	

ability (hemostasis) *									
CA-125 *	8	7	31	21	61	65	56	39	59
Estrogen levels *	7	7	27	12	53	76	91	76	102

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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)	
Iron levels (Ferritin) *	0.8%	1%	1.4%	0.8%	6.4%	11.8%	24%	22%	25.3%	
Blood levels (Hemoglobin) *	1%	0.2%	1.2%	1.8%	5.4%	11.4%	22.4%	22.2%	25.5%	
Platelet (Thrombocyte) count *	0.8%	1%	3%	2.2%	11.2%	18.2%	19%	14.2%	15.2%	
Genetic and molecular markers of blood clotting ability (hemostasis) *	0.6%	0.8%	2.8%	4%	11.8%	17.2%	17%	13.6%	14.6%	
CA-125 *	1.6%	1.4%	6.2%	4.2%	12.2%	13%	11.2%	7.8%	11.8%	
Estrogen levels *	1.4%	1.4%	5.4%	2.4%	10.6%	15.2%	18.2%	15.2%	20.4%	

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Category 6: Life impact

In this category, we ask you to rate outcomes that are related to a person`s life.

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

If you are not familiar with an outcome, please choose "I don't know this outcome".

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
Health impact on quality of life/Health related quality of life (this includes several domains, such as physical functioning, social functioning and mental health) *	3	1	1	2	2	7	48	107	330	
Sexual functioning (this includes several items, such as sexual satisfaction, desire, lubrication and so on) *	2	4	2	3	5	21	77	144	235	

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Response distribution (%)

	Extremely	Very	Unimportant	Maybe	Unsure	Maybe	Important	Very	Extremely	I d

	unimportant (1)	unimportant (2)	(3)	unimportant (4)	unimportant or important (5)	important (6)	(7)	important (8)	important (9)	kr th outo
Health impact on quality of life/Health related quality of life (this includes several domains, such as physical functioning, social functioning and mental health) *	0.6%	0.2%	0.2%	0.4%	0.4%	1.4%	9.6%	21.4%	65.9%	0
Sexual functioning (this includes several items, such as sexual satisfaction, desire, lubrication and so on) *	0.4%	0.8%	0.4%	0.6%	1%	4.2%	15.4%	28.7%	46.9%	1.

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

In this category, we ask you to rate outcomes related to the treatment 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.

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

If you are not familiar with an outcome, please choose "I don't know this outcome".

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)	
How well a patient follows a treatment (Patient compliance) *	4	1	3	6	10	30	153	131	149	
Patient satisfaction with treatment *	5	4	1	6	6	14	69	144	243	
Discomfort/pain during procedure *	4	1	2	7	11	30	103	126	202	
Recovery time after procedure *	3	5	4	6	12	35	116	124	175	
How much better the worst symptom gets (Symptom relief rate for the most bothersome symptom) *	4	2	0	1	7	15	51	149	257	
How long it takes for the worst symptom to come back (Time to symptom recurrence for most bothersome symptom) *	6	1	1	3	7	14	71	149	232	
How long it takes for any	6	3	1	0	5	28	94	140	207	

symptom to come back (Time to symptom recurrence) *									
Technical energy used during procedure *	5	7	9	16	53	75	92	65	77
Time it takes to perfom a procedure (Procedure time) *	2	6	18	30	42	99	117	62	73
Having to stop a procedure before it was finished (Premature termination of procedure) *	5	2	7	9	32	62	137	72	85
Blood loss during operation *	4	1	7	5	27	59	138	91	109
Need for blood transfusion *	8	2	5	10	27	56	117	90	114
Size of adenomyosis lesion *	3	2	0	5	18	38	103	127	172
Volume (size) of the uterus *	3	0	0	8	28	59	109	114	139
Weight of removed tissue *	3	2	4	18	48	78	116	71	98

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)	
How well a patient follows a treatment (Patient compliance) *	0.8%	0.2%	0.6%	1.2%	2%	6%	30.5%	26.1%	29.7%	
Patient satisfaction with treatment *	1%	0.8%	0.2%	1.2%	1.2%	2.8%	13.8%	28.7%	48.5%	
Discomfort/pain during procedure *	0.8%	0.2%	0.4%	1.4%	2.2%	6%	20.6%	25.1%	40.3%	
Recovery time after procedure *	0.6%	1%	0.8%	1.2%	2.4%	7%	23.2%	24.8%	34.9%	
How much better the worst symptom gets (Symptom relief rate for the most bothersome symptom) *	0.8%	0.4%	0%	0.2%	1.4%	3%	10.2%	29.7%	51.3%	
How long it takes for the worst symptom to come back (Time to symptom recurrence for most bothersome symptom) *	1.2%	0.2%	0.2%	0.6%	1.4%	2.8%	14.2%	29.7%	46.3%	
How long it takes for any symptom to come back (Time to symptom recurrence) *	1.2%	0.6%	0.2%	0%	1%	5.6%	18.8%	27.9%	41.3%	
Technical	1%	1.4%	1.8%	3.2%	10.6%	15%	18.4%	13%	15.4%	

energy used during procedure *									
Time it takes to perfom a procedure (Procedure time) *	0.4%	1.2%	3.6%	6%	8.4%	19.8%	23.4%	12.4%	14.6%
Having to stop a procedure before it was finished (Premature termination of procedure) *	1%	0.4%	1.4%	1.8%	6.4%	12.4%	27.3%	14.4%	17%
Blood loss during operation *	0.8%	0.2%	1.4%	1%	5.4%	11.8%	27.5%	18.2%	21.8%
Need for blood transfusion *	1.6%	0.4%	1%	2%	5.4%	11.2%	23.4%	18%	22.8%
Size of adenomyosis lesion *	0.6%	0.4%	0%	1%	3.6%	7.6%	20.6%	25.3%	34.3%
Volume (size) of the uterus *	0.6%	0%	0%	1.6%	5.6%	11.8%	21.8%	22.8%	27.7%
Weight of removed tissue *	0.6%	0.4%	0.8%	3.6%	9.6%	15.6%	23.2%	14.2%	19.6%

Category 8: Economy

In this category, we ask you to rate outcomes related to economic aspects of a treatment.

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

If you are not familiar with an outcome, please choose "I don't know this outcome".

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)	
Costs of treatment *	9	5	10	7	29	44	131	83	144	
How much the patient has to pay for a treatment (Patient costs) *	6	6	6	11	25	42	107	93	165	
Value-for-money of treatment (Cost-utility analysis) *	5	3	9	7	37	47	114	100	131	
Need for repeated or other treatment (Need for re-intervention) *	2	3	3	2	16	27	90	130	191	
Length of hospital stay *	2	5	17	15	26	60	140	102	96	

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)	
Costs of treatment *	1.8%	1%	2%	1.4%	5.8%	8.8%	26.1%	16.6%	28.7%	
How much the patient	1.2%	1.2%	1.2%	2.2%	5%	8.4%	21.4%	18.6%	32.9%	

has to pay for a treatment (Patient costs) *									
Value-for-money of treatment (Cost-utility analysis) *	1%	0.6%	1.8%	1.4%	7.4%	9.4%	22.8%	20%	26.1%
Need for repeated or other treatment (Need for re-intervention) *	0.4%	0.6%	0.6%	0.4%	3.2%	5.4%	18%	25.9%	38.1%
Length of hospital stay *	0.4%	1%	3.4%	3%	5.2%	12%	27.9%	20.4%	19.2%

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Category 9: Adverse outcomes

In this first category, we ask you to rate outcomes related to harms caused by a treatment.

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

If you are not familiar with an outcome, please choose "I don't know this outcome".

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 know th outc
Death *	8	5	0	3	11	13	36	59	285	8
All harms, injuries and toxic reactions are reported *	4	3	1	4	1	19	49	91	280	4
Infections *	6	3	1	1	6	25	84	118	212	4

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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 know th outc
Death *	1.6%	1%	0%	0.6%	2.2%	2.6%	7.2%	11.8%	56.9%	16.
All harms, injuries and toxic reactions are reported *	0.8%	0.6%	0.2%	0.8%	0.2%	3.8%	9.8%	18.2%	55.9%	9.8
Infections *	1.2%	0.6%	0.2%	0.2%	1.2%	5%	16.8%	23.6%	42.3%	9

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Category 10: Reporting Items

Strictly speaking, the following items are not outcomes. But they provide information on the participants in a study.

This category contains items that describe what type of patients are included in a study. This could be relevant when we want to compare different studies.

Please rate how important you find it that the following items are reported in all 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)

Presence of endometriosis *	7	0	1	0	4	17	48	120	298
Presence of fibroids (myoma) *	6	3	1	1	12	33	80	114	209
Participant`s wish to become pregnant in the future *	9	2	4	5	11	27	63	104	261
That adenomyosis is described/classified with a unanimous classification *	2	2	1	1	31	33	76	96	201
What treatments for adenomyosis have been tried previously *	6	3	2	1	7	28	106	135	199

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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)
Presence of endometriosis *	1.4%	0%	0.2%	0%	0.8%	3.4%	9.6%	24%	59.5%
Presence of fibroids (myoma) *	1.2%	0.6%	0.2%	0.2%	2.4%	6.6%	16%	22.8%	41.7%
Participant`s wish to become pregnant in the future *	1.8%	0.4%	0.8%	1%	2.2%	5.4%	12.6%	20.8%	52.1%
That adenomyosis is described/classified with a unanimous classification *	0.4%	0.4%	0.2%	0.2%	6.2%	6.6%	15.2%	19.2%	40.1%
What treatments for adenomyosis have been tried previously *	1.2%	0.6%	0.4%	0.2%	1.4%	5.6%	21.2%	26.9%	39.7%

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Thank you very much for your participation!

After we have collected enough responses, we will analyse which outcomes made it to the core outcome set, and which were excluded. The outcomes that did not reach an agreement, or new ones that were suggested, will be presented to you in a second survey.

We hope to see you back in the next round! The second survey will likely be shorter- but equally important. And only people that have participated now can go to the next round.

Meanwhile, let others know about COSAR and share the survey link with them!

COSAR
CORE OUTCOME SET FOR ADENOMYOSIS RESEARCH

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