

Themes	Outcomes	R1 - Panel SuRa		R1 - Panel GaNu		R1 - Panel Pa		R1 - Overall		R1 results
		<i>importance</i>		<i>importance</i>		<i>importance</i>		<i>importance</i>		Domain retained
		High (%)	Low (%)	High (%)	Low (%)	High (%)	Low (%)	High (%)	Low (%)	
2	Faecal diversion or proctectomy	97	0	98	0	96	0	97	0	yes
6	Death	97	3	100	0	91	5	96	3	yes
2	Development of a new fistula	89	0	97	0	92	0	93	0	yes
2	Incontinence to solid stool	89	0	94	0	93	1	92	0	yes
2	Perianal related hospitalisation	89	0	94	0	91	3	91	1	yes
2	Incontinence to liquid stool	83	0	92	0	96	0	91	0	yes
2	Perianal abscess on clinical assessment after intervention	86	2	89	0	92	6	89	3	yes
2	Surgical re-intervention	89	2	91	0	86	5	89	2	yes
2	Recurrence of fistula	86	0	94	0	81	0	87	0	yes
6	Medical complications specific to the immunosuppression (e.g. opportunistic infections, cancers)	79	0	97	0	83	9	86	3	yes
3	Unable attend school/work	84	0	92	0	81	1	86	1	yes
6	Safety (adverse events) and toxicity	83	0	88	0	77	3	82	1	yes
2	Pads for continence/leakage	73	0	91	0	81	3	82	1	yes
3	Social interaction avoidance	65	3	82	0	89	6	79	3	yes

3	Lifestyle alterations (pain/restriction of activities)	76	2	85	0	75	8	78	3	yes
6	Neurological complications	73	6	85	6	76	12	78	8	yes
4	Abscess on MRI following treatment	73	5	91	0	68	3	77	2	yes
3	Restriction of sexual activity	63	3	79	0	86	3	77	2	yes
2	Anal pain	63	3	80	2	83	0	76	1	yes
4	Fistula response on MRI imaging	65	11	91	2	72	5	76	6	yes
6	Cardio-respiratory complications	70	3	76	6	81	7	76	5	yes
3	Limitation to moderate activities	70	0	74	0	79	1	74	1	yes
3	Physically restricted in self care	62	2	82	0	78	6	74	3	yes
4	# Fistula T2 hyperintensity on MRI	63	6	74	2	82	1	74	3	yes
1	Patient-reported reduction in fistula drainage	65	3	74	0	79	1	73	2	yes
3	Feeling depressed & down and hopelessness	59	5	79	2	79	7	73	4	yes
7	Duration of healing/improvement	73	3	80	0	66	16	73	7	yes
3	Modifying how you walk, sit or stand because of your fistula	60	5	68	2	83	9	71	5	yes
3	Anxiety & worries	57	8	74	3	81	1	71	4	yes
6	Allergic reaction	70	2	79	5	64	5	71	4	yes

3	Avoidance of intimacy	63	2	77	0	71	3	71	2	yes
3	Change in lifestyle based on toileting needs	65	0	68	0	77	5	70	2	yes
2	# Wound infection	43	6	74	2	90	0	70	2	yes
3	Change in general health - psychological	56	3	74	0	78	4	70	2	yes
6	Surgical complications specific to the surgical procedure (e.g. plug extrusion)	57	6	68	2	79	1	69	3	yes
3	Embarrassment & feeling isolated	62	2	74	2	68	8	68	4	yes
2	Discrimination between passing stool and gas	57	6	70	0	76	3	68	3	yes
1	Complete fistula healing assessed clinically	67	2	82	3	57	15	68	7	yes
3	Concerns about and impact on fertility, birth, parenthood and family	52	3	71	2	75	7	67	4	yes
4	MRI assessment of fistula volume	46	19	76	3	76	1	67	7	yes
4	# Fistula T1 enhancement on MRI	43	14	73	6	81	3	67	7	yes
3	Change in general health - physical	52	3	65	3	79	3	66	3	yes
6	Grading system for surgical complications e.g. Clavien-Dindo	59	11	62	14	76	5	66	10	yes
3	Sleep disturbance	51	6	64	8	80	4	66	6	yes
3	# Lethargy and fatigue	46	6	62	6	85	3	65	5	yes
5	Fever	49	10	74	5	71	4	65	6	yes

2	Faecal urgency	46	5	67	0	79	4	65	3	yes
3	Tolerability of treatment	56	2	64	5	73	5	64	4	yes
3	A feeling of being unhygienic	46	8	64	5	80	1	64	5	yes
1	Rectal mucosal healing	57	11	74	2	58	5	63	6	yes
6	# Urinary complications	44	0	59	5	84	3	63	3	yes
1	Local perianal inflammation/induration assessed clinically	48	5	58	3	82	0	63	3	yes
7	* Biologic free remission	68	2	56	14	64	6	63	7	yes
3	* A quality of life score e.g. Short form survey 36 (SF-36)	56	6	64	11	68	2	63	6	yes
2	Plug for continence/leakage	49	6	61	6	76	1	63	5	yes
3	Modifying travel	48	5	65	2	72	3	62	3	yes
2	Mucus leakage	44	3	68	2	71	0	62	1	yes
1	Closure of internal opening	54	19	56	11	71	6	61	12	yes
7	Financial implications	48	5	50	6	83	0	61	4	yes
5	Time to loss of response to medical treatments	38	13	68	6	72	4	60	8	yes
1	Closure of all the external openings on clinical examination	52	8	62	6	64	2	60	5	no
1	Clinical assessment of drainage either spontaneously or on gentle finger pressure	33	6	56	8	84	5	59	6	yes

4	* An activity based MRI score e.g. Van Assche Score	30	24	68	11	75	4	59	12	yes
1	# Development of perianal features of Crohn's (other than fistula)	49	16	52	8	72	10	59	11	yes
1	# A validated score to assess perianal disease activity e.g. Perianal disease activity index (PDAI)	38	22	58	8	77	3	59	11	yes
2	Incontinence to wind	44	13	61	5	69	0	58	6	no
7	Recovery time after intervention	40	6	55	3	77	0	58	3	yes
7	Antibiotic free remission	49	5	53	8	68	5	57	6	no
3	Restricted clothing choices	38	3	53	8	75	3	56	4	yes
7	Increasing analgesia	48	0	59	2	60	12	56	5	no
1	≥50% tracts not draining on clinical examination	37	22	50	5	75	11	56	12	yes
4	MRI assessment of rectum (proctitis)	32	29	50	11	82	0	56	13	yes
2	* A combined faecal incontinence score e.g. the Vaizey Score, Cleveland Clinic Incontinence score, Faecal Incontinence Severity Index (FISI)	40	21	62	11	62	0	55	10	yes
3	Patient perception of continence compared to others OR baseline	44	2	55	9	62	14	54	9	no
3	Decisional regret of treatment choice	44	6	56	3	59	5	53	5	no
3	Body detachment	40	6	58	5	61	6	53	6	no
3	Concern over further intervention	35	6	53	8	70	1	53	5	yes
3	Irritable, frustrated and angry	33	11	53	8	70	1	53	6	yes

2	Tenesmus or incomplete evacuation	37	8	52	5	67	1	52	4	no
2	# Anal bleeding	22	24	53	6	76	5	52	11	yes
3	Limitation to vigorous activities (e.g. running, lifting heavy objects, participating in strenuous sports)	32	6	53	5	67	10	51	7	no
1	Partial fistula healing assessed clinically	33	6	42	6	74	1	51	5	yes
4	# Fistula response on endoanal USS	17	43	58	20	71	2	49	21	yes
5	Objective blood markers of inflammation	25	24	48	12	65	1	47	12	no
2	Increased frequency of loose stool	27	10	50	3	59	4	46	6	no
6	Rash or other skin/hair problems	32	17	45	11	59	4	46	11	no
5	C-reactive protein (CRP)	24	27	47	12	62	11	46	16	no
6	Nausea or vomiting	38	14	50	15	48	6	46	12	no
5	Non-inflammatory blood markers (<i>related biologics</i>)	27	25	45	18	61	3	45	15	no
7	Cost effectiveness	29	17	44	12	54	5	42	12	no
5	Instability of weight (assessed by BMI)	30	29	39	15	42	6	37	16	no
7	Use anti-diarrhoeal drugs	16	22	29	27	58	5	34	18	no

THEME KEY

- 1 Fistula response to treatment (symptoms)
- 2 Direct impact of fistula on the patient

- 3 Impact on the patient as a person
- 4 Assessment with imaging techniques (scans)
- 5 Fistula response to treatment (tests)
- 6 Safety implications related to treatment
- 7 Impact on patient over time

*SMG decision to change the name (or lay description) based on heterogeneity or comments by participants

Items were retained due to polarising views/heterogeneity or comments by participants

Supplementary file 2. Round 1 voting