

## S1: Characteristics and management of infants treated in participating and non-participating sites

	Non-participating sites	Participating sites	
	N=53	N=252	
	n(%)*	n(%)*	p-value
<b>Diagnosed in a low volume centre (&lt; national median number of cases/year)</b>			<0.001
No	0 (0.0%)	141 (56.0%)	
Yes	53 (100.0%)	111 (44.0%)	
<b>Ethnicity</b>			0.68
White	44 (84.6%)	216 (86.7%)	
BME	8 (15.4%)	33 (13.3%)	
<b>Gestational age at birth</b>			0.10
Term	49 (94.2%)	215 (86.0%)	
Pre-term	3 (5.8%)	35 (14.0%)	
<b>Birthweight</b>			0.060
2500g or more	49 (96.1%)	211 (86.8%)	
Less than 2500g	2 (3.9%)	32 (13.2%)	
<b>Sex</b>			0.46
Male	38 (73.1%)	196 (77.8%)	
Female	14 (26.9%)	56 (22.2%)	
<b>Family history of HD</b>			<0.001
No	41 (78.8%)	234 (94.0%)	
Yes	11 (21.2%)	15 (6.0%)	
<b>Associated anomaly</b>			0.14
Isolated HD	47 (88.7%)	184 (73.6%)	
Down's syndrome	2 (3.8%)	26 (10%)	
Other identified syndrome	2 (3.8%)	21 (8%)	
Isolated additional anomaly	2 (3.8%)	19 (7.6%)	
<b>Age at presentation</b>			0.94
1-7 days	47 (88.7%)	219 (86.9%)	
8-28 days	2 (3.8%)	11 (4.4%)	
More than 28 days	4 (7.5%)	22 (8.7%)	

\* Percentage of those with complete data

### S1: Characteristics and management of infants treated in participating and non-participating sites - Continued

	Non-participating sites	Participating sites	
	N=53	N=252	
	n(%)*	n(%)*	p-value
<b>Age at diagnosis</b>			0.82
<31 days	47 (88.7%)	213 (85.2%)	
31-60 days	2 (3.8%)	10 (4.0%)	
61-90 days	3 (5.7%)	13 (5.2%)	
91-120 days	1 (1.9%)	4 (1.6%)	
121-150 days	0 (0.0%)	2 (0.8%)	
>150 days	0 (0.0%)	8 (3.2%)	
<b>Transition zone (as defined at surgery)</b>			0.35
Rectosigmoid	31 (67.4%)	168 (74.3%)	
Long segment (proximal to sigmoid colon)	11 (23.9%)	49 (21.7%)	
Total colonic aganglionosis	4 (8.7%)	9 (4.0%)	
<b>Stoma created prior to pull-through</b>			0.18
No	38 (71.7%)	156 (61.9%)	
Yes	15 (28.3%)	96 (38.1%)	
<b>Definitive surgery within a year of diagnosis</b>			0.95
No	4 (7.7%)	17 (7%)	
Yes	48 (92.3%)	225 (93%)	
<b>Staged definitive procedure</b>			0.14
No	38 (77.6%)	153 (66.8%)	
Yes	11 (22.4%)	76 (33.2%)	
<b>First approach to the pull-through</b>			0.034
Definitive surgery not performed prior to one year	5 (9.6%)	17 (7%)	
Open	17 (32.7%)	87 (36%)	
Laparoscopic	9 (17.3%)	42 (17.4%)	
Trans-anal	3 (5.8%)	50 (20.7%)	
Combined laparoscopic and trans-anal	18 (34.6%)	46 (19.0%)	
<b>Rectal dissection technique</b>			0.007
Submucosal (Soave)	29 (60.4%)	119 (52%)	
Peri-rectal (Swenson)	9 (18.8%)	17 (7.4%)	
Posterior (Duhamel)	10 (20.8%)	93 (40.6%)	
	<b>Median (IQR)</b>	<b>Median (IQR)</b>	
<b>Weight at stoma formation</b>			0.23
Grams	3800 (3340, 4200)	3500 (3000, 4000)	
<b>Weight at definitive surgery</b>			0.052
Kilograms	6.12 (5.2, 6.92)	5.43 (4.21, 6.55)	

\* Percentage of those with complete data

## S2: One year outcomes for infants who underwent definitive surgery in participating and non-participating sites

	Non-participating site	Participating site	
	N=36	N=204	
	n(%)*	n(%)*	p-value
<b>Revision surgery within a year of diagnosis</b>			0.42
No	30 (100.0%)	187 (97.9%)	
Yes	0 (0.0%)	4 (2.1%)	
<b>Post pull-through stoma within a year of diagnosis</b>			0.11
No	25 (80.6%)	160 (90.4%)	
Yes	6 (19.4%)	17 (9.6%)	
<b>Post-operative HAE suspected</b>			0.70
No	25 (71.4%)	137 (68.2%)	
Yes	10 (28.6%)	64 (31.8%)	
<b>One or more unplanned reoperations within a year of diagnosis</b>			0.72
No	31 (88.6%)	165 (85.9%)	
Yes	4 (11.4%)	27 (14.1%)	
<b>Total number of unplanned operations within a year of diagnosis</b>			0.81
None	31 (88.6%)	165 (85.9%)	
One	3 (8.6%)	15 (7.8%)	
Two	1 (2.9%)	8 (4.2%)	
Three	0 (0.0%)	4 (2.1%)	

\*Percentage of those with complete data

### S3: Characteristics and management of infants treated in participating sites with and without five to eight year data

	No data returned	Data returned	
	N=13	N=239	
	n(%)*	n(%)*	p-value
<b>Diagnosed in a low volume (&lt; median) centre</b>			0.46
No	6 (46.2%)	135 (56.5%)	
Yes	7 (53.8%)	104 (43.5%)	
<b>Ethnicity</b>			0.28
White	10 (76.9%)	206 (87.3%)	
BME	3 (23.1%)	30 (12.7%)	
<b>Gestational age at birth</b>			0.26
Term	9 (75.0%)	206 (86.6%)	
Pre-term	3 (25.0%)	32 (13.4%)	
<b>Birthweight</b>			0.21
2500g or more	9 (75.0%)	202 (87.4%)	
Less than 2500g	3 (25.0%)	29 (12.6%)	
<b>Sex</b>			0.54
Male	11 (84.6%)	185 (77.4%)	
Female	2 (15.4%)	54 (22.6%)	
<b>Family history of HD</b>			0.35
No	13 (100.0%)	221 (93.6%)	
Yes	0 (0.0%)	15 (6.4%)	
<b>Associated anomaly</b>			0.39
Isolated HD	7 (58.3%)	177 (74.4%)	
Down's Syndrome	3 (23%)	23 (10%)	
Other identified syndrome	1 (8%)	20 (8%)	
Isolated additional anomaly	1 (8.3%)	18 (7.6%)	
<b>Age at presentation (days)</b>			0.55
1-7 days	10 (76.9%)	209 (87.4%)	
8-28 days	1 (7.7%)	10 (4.2%)	
More than 28 days	2 (15.4%)	20 (8.4%)	
<b>Age at diagnosis</b>			0.022
<31 days	9 (69.2%)	204 (86.1%)	
31-60 days	0 (0.0%)	10 (4.2%)	
61-90 days	3 (23.1%)	10 (4.2%)	
91-120 days	1 (7.7%)	3 (1.3%)	
121-150 days	0 (0.0%)	2 (0.8%)	
>150 days	0 (0.0%)	8 (3.4%)	
<b>Transition zone (as defined at surgery)</b>			0.75
Rectosigmoid	9 (75.0%)	159 (74.3%)	
Long segment (proximal to sigmoid colon)	3 (25.0%)	46 (21.5%)	
Total colonic aganglionosis	0 (0.0%)	9 (4.2%)	

\* Percentage of those with complete data

BME – Black or other minority ethnicity

### S3: Characteristics and management of infants treated in participating sites with and without five to eight year data - Continued

	No data returned N=13	Data returned N=239	
	n(%)*	n(%)*	p-value
<b>Stoma created prior to pull-through</b>			0.54
No	7 (53.8%)	149 (62.3%)	
Yes	6 (46.2%)	90 (37.7%)	
<b>Definitive surgery (including permanent stoma) confirmed as occurring within one year of diagnosis</b>			0.31
No	0 (0.0%)	17 (7.4%)	
Yes	12 (100.0%)	213 (92.6%)	
<b>Staged definitive procedure</b>			0.52
No	7 (58.3%)	146 (67.3%)	
Yes	5 (41.7%)	71 (32.7%)	
<b>First approach to the pull-through</b>			0.56
Pull-through procedure not performed within one year of diagnosis	0 (0.0%)	17 (7.4%)	
Open	6 (50.0%)	81 (35.2%)	
Laparoscopic	3 (25.0%)	39 (17.0%)	
Trans-anal	2 (16.7%)	48 (20.9%)	
Combined laparoscopic and trans-anal	1 (8.3%)	45 (19.6%)	
<b>Rectal dissection technique</b>			0.32
Submucosal (Soave)	5 (41.7%)	114 (52.5%)	
Peri-rectal (Swenson)	0 (0.0%)	17 (7.8%)	
Posterior (Duhamel)	7 (58.3%)	86 (39.6%)	
	<b>Median (IQR)</b>	<b>Median (IQR)</b>	
<b>Weight at stoma formation</b>			0.21
Grams	4100 (3500, 5000)	3475 (3000, 4000)	
<b>Weight at definitive surgery</b>			0.99
Kilograms	5.5 (4.5, 7.32)	5.4 (4.2, 6.55)	

\*Percentage of those with complete data

#### S4: Outcomes at one year post diagnosis for children with and without five to eight year data returned

Based upon those children who had undergone definitive surgery in a participating hospital, and for whom one-year outcomes data had been returned.

	No data returned	Data returned	
	N=11 <sup>#</sup>	N=193 <sup>#</sup>	
	n(%) <sup>*</sup>	n(%) <sup>*</sup>	p-value
<b>Revision surgery within a year of diagnosis</b>			0.63
No	10 (100.0%)	177 (97.8%)	
Yes	0 (0.0%)	4 (2.2%)	
<b>Post pull-through stoma within a year of diagnosis</b>			0.78
No	7 (87.5%)	153 (90.5%)	
Yes	1 (12.5%)	16 (9.5%)	
<b>Post-operative HAE suspected</b>			0.32
No	9 (81.8%)	128 (67.4%)	
Yes	2 (18.2%)	62 (32.6%)	
<b>One or more unplanned reoperation within a year of diagnosis</b>			0.65
No	9 (81.8%)	156 (86.2%)	
Yes	2 (18.2%)	25 (13.8%)	

<sup>#</sup> Those children who had undergone definitive surgery prior to one year of age, and for whom one-year outcomes data were returned

<sup>\*</sup> Percentage of those with complete data

## S5: Characteristics and management of infants with and without parental follow-up data

	No Parental Data	Parental Data	p-value
	N=157 n(%)*	N=83 n(%)*	
Low volume centre (<median number of cases/year)			0.006
No	97 (61.8%)	36 (43.4%)	
Yes	60 (38.2%)	47 (56.6%)	
Ethnicity			0.22
White	131 (84.5%)	74 (90.2%)	
Non-white	24 (15.5%)	8 (9.8%)	
Gestational age at birth			0.89
Term	136 (87.2%)	72 (87.8%)	
Pre-term	20 (12.8%)	10 (12.2%)	
Birthweight			0.77
2500g or more	132 (87.4%)	71 (88.8%)	
Less than 2500g	19 (12.6%)	9 (11.2%)	
Sex			0.65
Male	125 (79.6%)	64 (77.1%)	
Female	32 (20.4%)	19 (22.9%)	
Family history of Hirschsprung's disease			0.21
No	148 (95.5%)	75 (91.5%)	
Yes	7 (4.5%)	7 (8.5%)	
Associated anomaly			0.97
Isolated Hirschsprung's disease	120 (76.9%)	62 (75.6%)	
Syndromic	25 (16.0%)	14 (17.1%)	
Isolated additional anomaly	11 (7.1%)	6 (7.3%)	
Age at presentation (days)			0.23
1-7 days	139 (88.5%)	70 (84.3%)	
8-28 days	4 (2.5%)	6 (7.2%)	
More than 28 days	14 (8.9%)	7 (8.4%)	
Age at diagnosis			0.86
<31 days	131 (84.0%)	72 (86.7%)	
31-60 days	5 (3.2%)	4 (4.8%)	
61-90 days	10 (6.4%)	3 (3.6%)	
91-120 days	3 (1.9%)	1 (1.2%)	
121-150 days	1 (0.6%)	1 (1.2%)	
>150 days	6 (3.8%)	2 (2.4%)	
Transition zone (as defined at surgery)			0.64
Rectosigmoid	113 (75.8%)	52 (70.3%)	
Long segment (proximal to sigmoid colon)	30 (20.1%)	19 (25.7%)	
Total colonic aganglionosis	6 (4.0%)	3 (4.1%)	
Stoma created prior to pull-through			0.32
No	103 (65.6%)	49 (59.0%)	
Yes	54 (34.4%)	34 (41.0%)	
Definitive surgery confirmed as occurring prior to one year			0.27
No	9 (5.8%)	8 (9.6%)	

Yes	147 (94.2%)	75 (90.4%)	
Staged definitive procedure			0.66
No	103 (67.8%)	48 (64.9%)	
Yes	49 (32.2%)	26 (35.1%)	
First attempted approach to the pull-through			0.042
Pull-through procedure not performed prior to one year	9 (5.8%)	8 (9.6%)	
Open	57 (36.5%)	29 (34.9%)	
Laparoscopic	20 (12.8%)	21 (25.3%)	
Trans-anal	39 (25.0%)	11 (13.3%)	
Combined laparoscopic and trans-anal	31 (19.9%)	14 (16.9%)	
Rectal dissection technique			0.21
Submucosal (Soave)	81 (53.6%)	36 (48.0%)	
Peri-rectal (Swenson)	13 (8.6%)	3 (4.0%)	
Posterior (Duhamel)	57 (37.7%)	36 (48.0%)	
Weight(g) at stoma formation, median (IQR)	3622 (3040, 4200)	3550 (2700, 3800)	0.30
Weight at definitive surgery(kg), median (IQR)	5.5 (4.48, 6.64)	5.15 (4.03, 6.405)	0.32

\*Percentage of those with complete data