



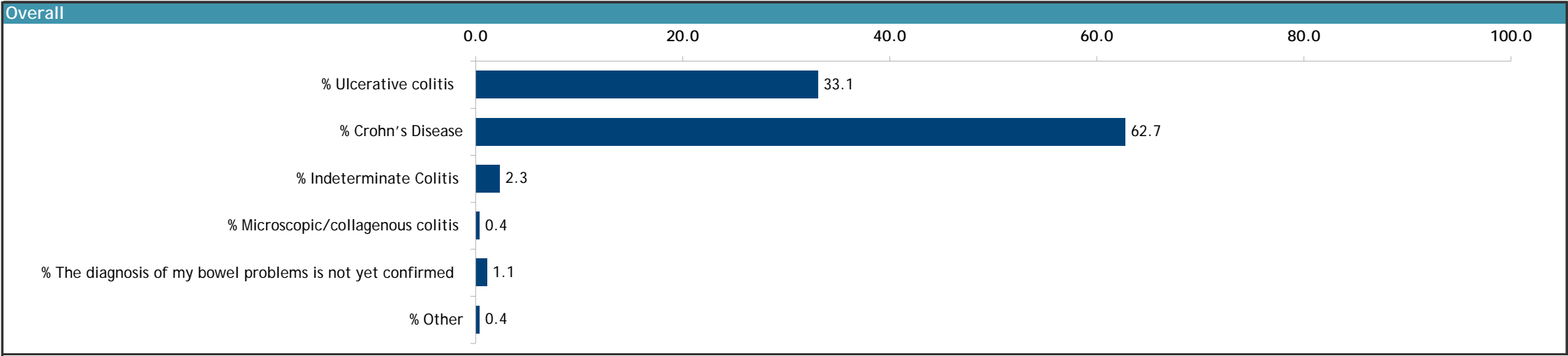
Detailed charts & tables



Section A : Firstly, we would like to focus on some details of your experience with IBD.



Q1: What form of IBD do you have?



	% Ulcerative colitis	% Crohn's Disease	% Indeterminate Colitis	% Microscopic/collagenous colitis	% The diagnosis of my bowel problems is not yet confirmed	% Other	Resps
EFCCA Overall	33			63		2 0 10	4644

Gender	% Ulcerative colitis	% Crohn's Disease	% Indeterminate Colitis	% Microscopic/collagenous colitis	% The diagnosis of my bowel problems is not yet confirmed	% Other	Resps
Male	36			61		2 10	1542
Female	32			64		2 1 10	3086
Not Stated	38			50		13	16



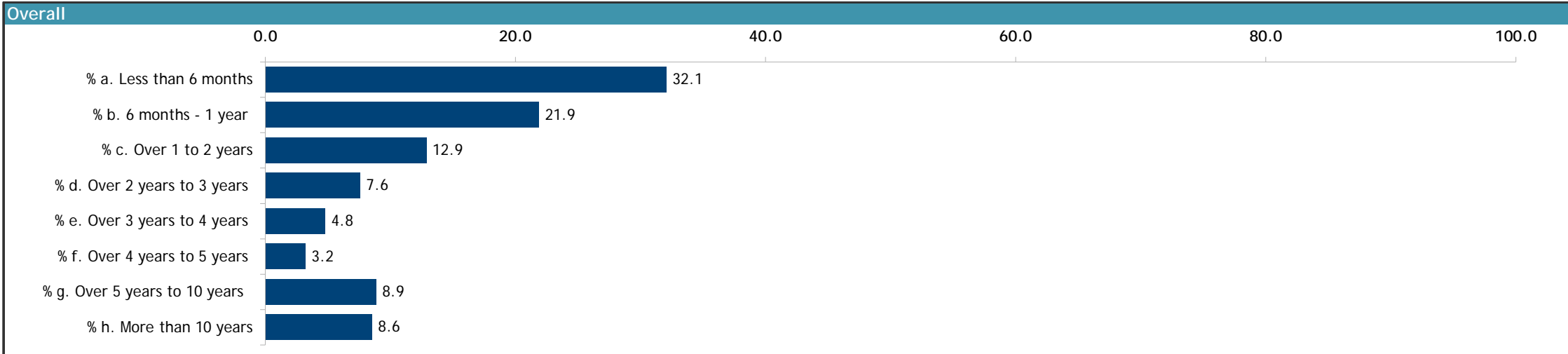
Q1: What form of IBD do you have?

Age Group	% Ulcerative colitis	% Crohn's Disease	% Indeterminate Colitis	% Microscopic/collagenous colitis	% The diagnosis of my bowel problems is not yet confirmed	% Other	Resps
<18 yrs	29			65		2 0 1 2	162
19-34	33			63		3 0 1 0	1999
35-54	34			62		2 1 1 0	2012
55+	34			62		2 1 1 0	463

Employment and Disability Status	% Ulcerative colitis	% Crohn's Disease	% Indeterminate Colitis	% Microscopic/collagenous colitis	% The diagnosis of my bowel problems is not yet confirmed	% Other	Resps
Fully employed	37			59		2 0 1 0	2218
Under-employed due to IBD	28			67		4 0 1 0	458
Un-employed due to IBD	25			70		3 0 1 1	387
Student	35			60		2 0 1 1	672
Retired	26			70		2 1 1 0	256
Disabled	18			79		2 0 1 0	649
Seeking disability	33			63		2 0 1 0	181
Unable to receive disability status	24			70		3 0 1 1	324
Other	33			62		2 0 1 1	460
N/A	39			56		1 1 2 0	193



Q2: How long after you first began to notice symptoms (that you now recognise as related to IBD), did it take to receive your final diagnosis?



	a.	b.	c.	d.	e.	f.	g.	h.	Resps
EFCCA Overall	32	22	13	8	5	3	9	9	4619

Gender	a.	b.	c.	d.	e.	f.	g.	h.	Resps
Male	33	23	12	8	4	2	8	9	1532
Female	31	21	13	7	5	4	9	8	3071
Not Stated	56	6	0	13	0	6	0	19	16



Q2: How long after you first began to notice symptoms (that you now recognise as related to IBD), did it take to receive your final diagnosis?

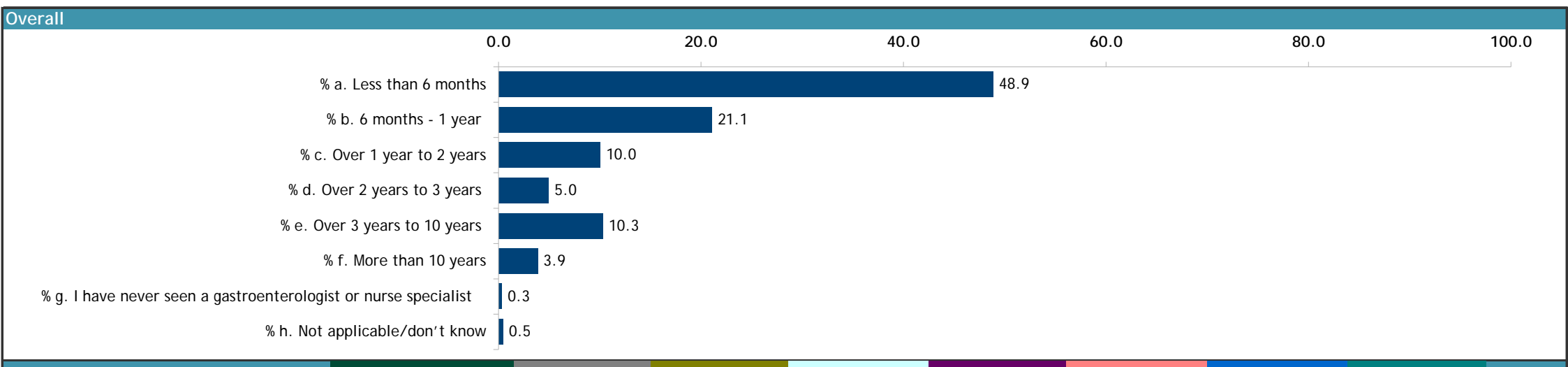
Age Group	a.	b.	c.	d.	e.	f.	g.	h.	Resps
<18 yrs	40	26	13	10	5	3	3	1	160
19-34	33	25	13	7	5	3	8	4	1989
35-54	32	19	13	7	4	3	10	12	2003
55+	25	19	13	9	6	4	9	15	459

Employment and Disability Status	a.	b.	c.	d.	e.	f.	g.	h.	Resps
Fully employed	32	23	14	7	5	3	9	7	2209
Under-employed due to IBD	27	17	14	11	5	4	11	12	457
Un-employed due to IBD	28	24	13	9	4	4	8	10	384
Student	39	25	12	7	5	2	6	3	667
Retired	27	19	10	11	6	3	9	16	252
Disabled	29	19	12	8	6	4	11	12	644
Seeking disability	31	24	13	13	2	3	4	11	181
Unable to receive disability status	22	21	15	7	6	6	11	10	321
Other	36	21	10	8	5	3	7	9	457
N/A	37	19	12	5	5	1	10	11	193

Type of IBD	a.	b.	c.	d.	e.	f.	g.	h.	Resps
Ulcerative colitis	46	22	10	6	3	3	6	5	1516
Crohn's Disease	26	22	15	8	6	3	10	10	2901
Indeterminate Colitis	28	15	13	10	2	6	10	16	107
Microscopic/collagenous colitis	28	28	6	11	0	6	22		18
Not yet confirmed	8	23	8	4	4	6	13	33	48
Other	6	28	6	22	0	22	17		18



Q3: How long after your IBD-related symptoms began did it take for you to first see a specialist (for example, gastroenterologist, nurse, IBD specialist) who was familiar with IBD?



	a.	b.	c.	d.	e.	f.	g.	h.	Resps
EFCCA Overall	49	21	10	5	10	4	0	0	4637

Gender	a.	b.	c.	d.	e.	f.	g.	h.	Resps
Male	52	22	9	5	8	3	0	0	1539
Female	47	21	11	5	11	4	0	0	3082
Not Stated	50	6	19	6	13	0	6	0	16



Q3: How long after your IBD-related symptoms began did it take for you to first see a specialist (for example, gastroenterologist, nurse, IBD specialist) who was familiar with IBD?

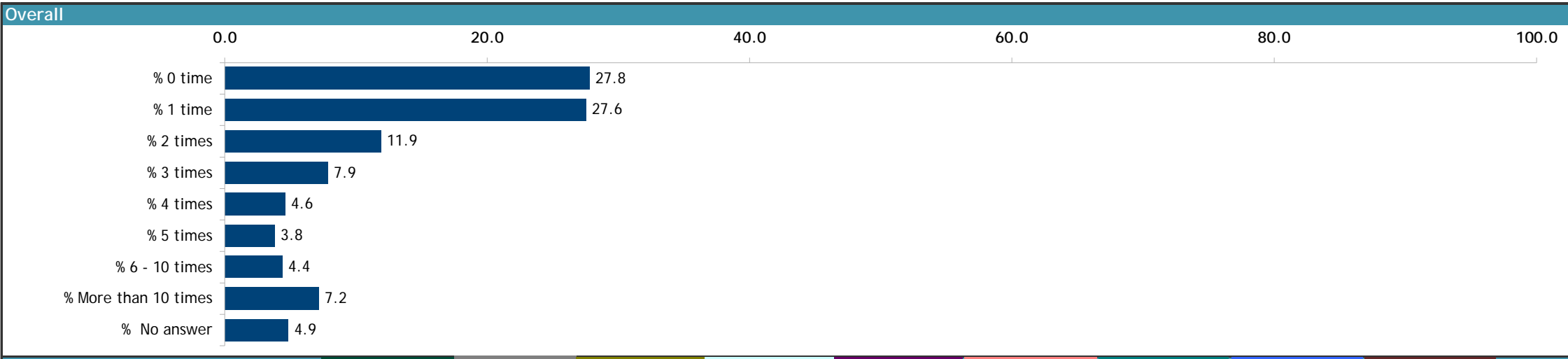
Age Group	a.	b.	c.	d.	e.	f.	g.	h.	Resps		
<18 yrs	63					19	8	4	5	10	163
19-34	49				24	10	4	10	2	0	1995
35-54	49				19	9	6	10	6	0	2006
55+	44				20	12	5	11	7	0	465

Employment and Disability Status	a.	b.	c.	d.	e.	f.	g.	h.	Resps		
Fully employed	48				22	11	5	10	3	0	2210
Under-employed due to IBD	44				19	12	7	12	5	10	459
Un-employed due to IBD	44				20	10	6	13	5	10	387
Student	55				22	9	5	8	2	0	672
Retired	48				17	12	4	11	6	0	257
Disabled	42				20	11	7	12	6	0	648
Seeking disability	45				23	8	6	9	6	1	179
Unable to receive disability status	44				18	13	5	14	4	1	322
Other	52				19	7	5	11	5	0	461
N/A	57				18	8	4	8	5	1	194

Type of IBD	a.	b.	c.	d.	e.	f.	g.	h.	Resps		
Ulcerative colitis	60				20	7	4	6	2	0	1530
Crohn's Disease	43				22	12	6	13	5	0	2901
Indeterminate Colitis	46				22	7	1	15	5	4	108
Microscopic/collagenous colitis	39				28	6	0	22	6	0	18
Not yet confirmed	31				25	8	2	12	14	8	51
Other	28				17	11	11	22	11	0	18



Q4: Thinking back, how many times did you go to an emergency department or emergency clinic with IBD symptoms before you received a definitive diagnosis?



	% 0 time	% 1 time	% 2 times	% 3 times	% 4 times	% 5 times	% 6 - 10 times	% More than 10 times	% No answer	Resps
EFCCA Overall	28	28	12	8	5	4	4	7	5	4670

Gender	% 0 time	% 1 time	% 2 times	% 3 times	% 4 times	% 5 times	% 6 - 10 times	% More than 10 times	% No answer	Resps
Male	29	28	12	9	5	4	4	7	4	1549
Female	27	28	12	7	5	4	5	8	5	3093
Not Stated	21	11	18	7	0	4	0	39		28



Q4: Thinking back, how many times did you go to an emergency department or emergency clinic with IBD symptoms before you received a definitive diagnosis?

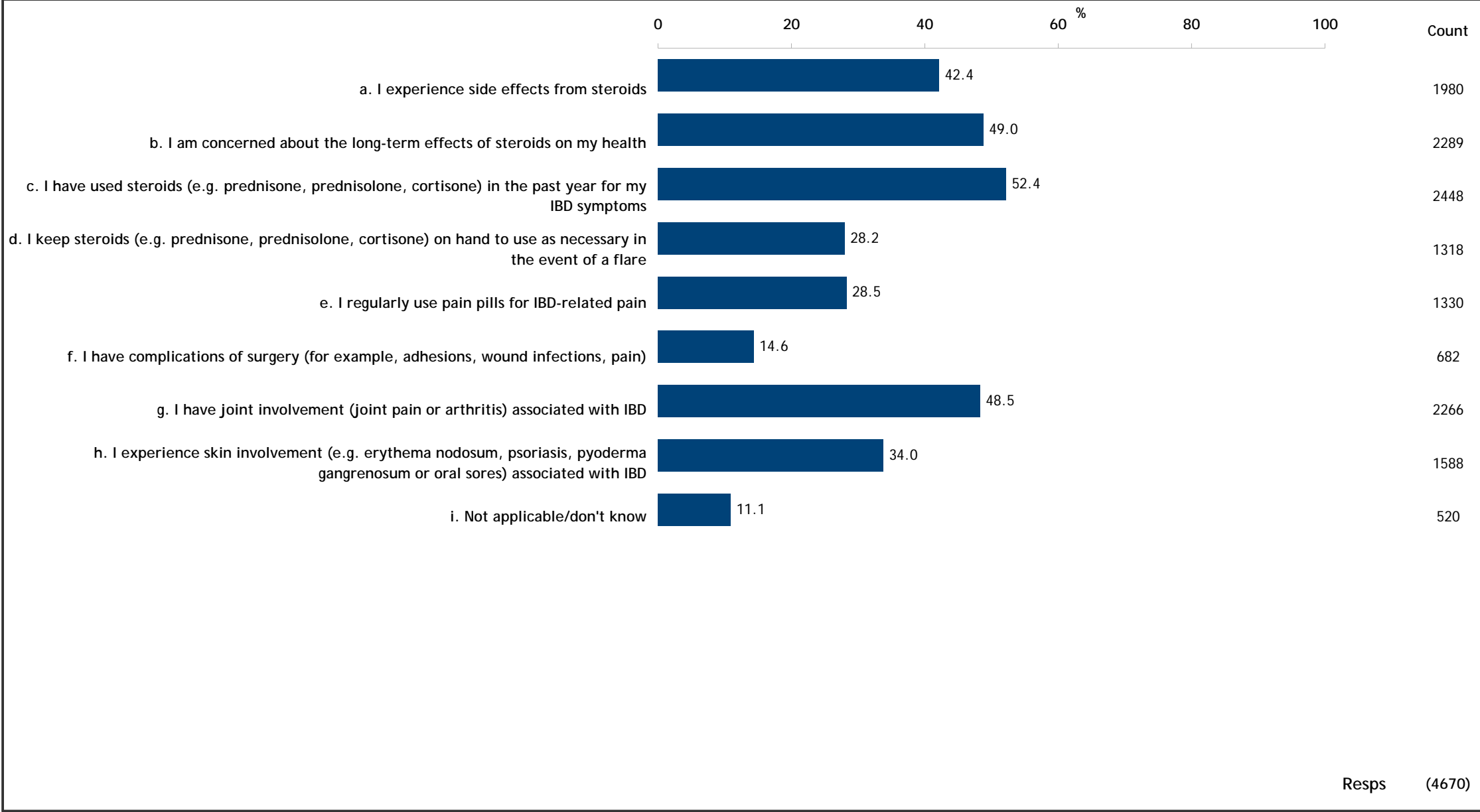
Age Group	% 0 time	% 1 time	% 2 times	% 3 times	% 4 times	% 5 times	% 6 - 10 times	% More than 10 times	% No answer	Resps
<18 yrs	22	26	14	13	7	7	2	6	4	163
19-34	25	29	14	8	5	4	5	7	4	2000
35-54	30	27	10	7	4	4	4	8	5	2020
55+	33	26	11	7	4	4	4	6	5	467

Employment and Disability Status	% 0 time	% 1 time	% 2 times	% 3 times	% 4 times	% 5 times	% 6 - 10 times	% More than 10 times	% No answer	Resps
Fully employed	31	27	12	7	5	3	4	7	4	2223
Under-employed due to IBD	23	31	11	7	5	5	6	8	5	459
Un-employed due to IBD	22	21	12	12	5	6	6	11	4	387
Student	26	26	14	10	5	4	5	6	5	673
Retired	28	28	12	8	5	5	4	9	2	258
Disabled	25	26	11	8	5	6	6	10	4	651
Seeking disability	22	22	18	9	5	4	5	8	7	184
Unable to receive disability status	26	26	9	10	5	4	5	10	5	324
Other	26	29	12	8	3	3	4	7	7	461
N/A	32	24	11	4	5	5	5	6	8	195

Type of IBD	% 0 time	% 1 time	% 2 times	% 3 times	% 4 times	% 5 times	% 6 - 10 times	% More than 10 times	% No answer	Resps
Ulcerative colitis	33	29	12	8	3.3	3	3	3	6	1535
Crohn's Disease	25	27	12	8	5.3	4	5	9	4	2914
Indeterminate Colitis	31	31	6	5	4.6	5	3	8	6	108
Microscopic/collagenous colitis	22	22	6	11.1	0	6	17	17	18	
Not yet confirmed	35	10	16	16	5.9	20	14	2	51	
Other	17	22	17	6	10	6	22	11	18	



Q5: Please tick any of the following that apply to you





Q5: Please tick any of the following that apply to you

Gender	a. I experience side effects from steroids	b. I am concerned about the long-term effects of steroids on my health	c. I have used steroids (e.g. prednisone, prednisolone, cortisone) in the past year for my IBD symptoms	d. I keep steroids (e.g. prednisone, prednisolone, cortisone) on hand to use as necessary in the event of a flare	e. I regularly use pain pills for IBD-related pain	f. I have complications of surgery (for example, adhesions, wound infections, pain)	g. I have joint involvement (joint pain or arthritis) associated with IBD	h. I experience skin involvement (e.g. erythema nodosum, psoriasis, pyoderma gangrenosum or oral sores) associated with IBD	i. Not applicable/don't know	Resps
Male	38.3	45.3	50.7	29.8	20.8	13.8	43.6	31.4	12.7	1549
Female	44.7	51.1	53.5	27.5	32.4	15.0	51.2	35.5	10.3	3093
Not Stated	17.9	28.6	28.6	17.9	17.9	14.3	21.4	14.3	10.7	28

Age Group	a.	b.	c.	d.	e.	f.	g.	h.	i.	Resps
<18 yrs	41.7	53.4	57.1	24.5	19.6	8.0	27.6	27.6	16.6	163
19-34	45.4	52.0	57.6	31.0	28.3	12.4	41.3	34.6	11.0	2000
35-54	41.1	48.0	48.7	26.9	29.9	16.7	55.8	33.6	10.5	2020
55+	36.8	40.9	46.3	24.4	27.2	17.8	56.5	36.4	12.8	467



Q5: Please tick any of the following that apply to you

Employment and Disability Status	a. I experience side effects from steroids	b. I am concerned about the long-term effects of steroids on my health	c. I have used steroids (e.g. prednisone, prednisolone, cortisone) in the past year for my IBD symptoms	d. I keep steroids (e.g. prednisone, prednisolone, cortisone) on hand to use as necessary in the event of a flare	e. I regularly use pain pills for IBD-related pain	f. I have complications of surgery (for example, adhesions, wound infections, pain)	g. I have joint involvement (joint pain or arthritis) associated with IBD	h. I experience skin involvement (e.g. erythema nodosum, psoriasis, pyoderma gangrenosum or oral sores) associated with IBD	i. Not applicable/don't know	Resps
Fully employed	38.1	46.5	50.3	26.6	22.9	11.8	43.8	30.8	12.6	2223
Under-employed due to IBD	50.3	54.2	59.9	32.0	39.9	23.5	59.7	41.0	4.8	459
Un-employed due to IBD	56.1	58.4	61.0	34.9	47.8	21.2	61.8	47.3	6.2	387
Student	45.8	52.7	60.3	33.1	25.0	10.4	36.4	31.1	10.7	673
Retired	40.7	41.9	41.1	26.4	29.5	27.9	59.3	36.8	11.6	258
Disabled	55.0	55.3	51.3	33.9	40.1	30.3	68.0	47.0	5.1	651
Seeking disability	53.3	61.4	65.2	35.9	46.2	18.5	62.0	42.4	7.1	184
Unable to receive disability status	49.1	54.3	56.5	33.0	40.1	21.0	65.4	45.7	7.1	324
Other	39.0	46.6	51.6	26.0	22.3	12.8	46.4	31.2	15.2	461
N/A	31.3	39.5	41.0	26.7	19.5	8.2	43.1	27.2	18.5	195

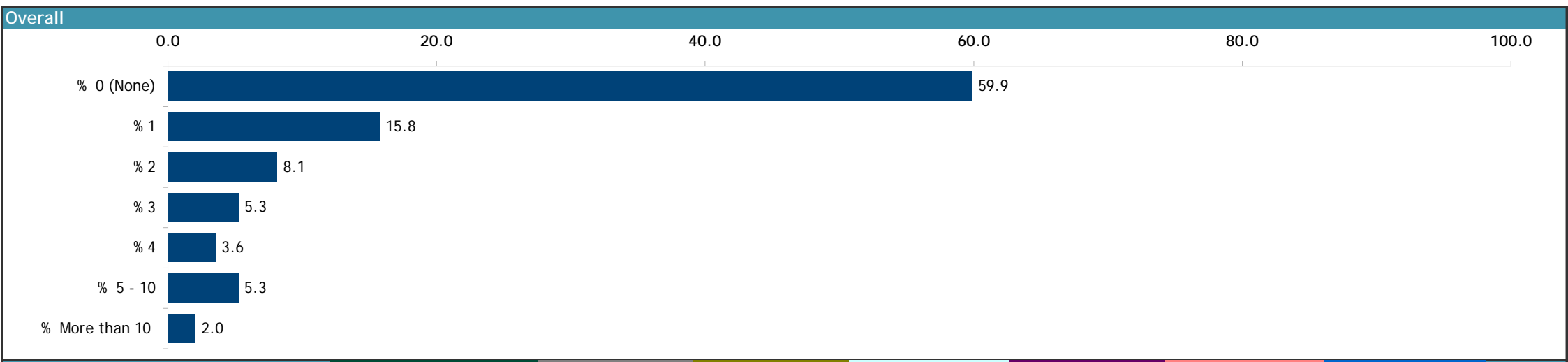
Type of IBD	a.	b.	c.	d.	e.	f.	g.	h.	i.	Resps
Ulcerative colitis	46.0	54.6	57.5	35.0	21.8	5.1	41.3	25.7	12.9	1535
Crohn's Disease	41.0	46.8	50.5	25.1	31.2	20.0	52.4	38.4	9.9	2914
Indeterminate Colitis	49.1	48.1	55.6	26.9	41.7	10.2	49.1	38.9	10.2	108
Microscopic/collagenous colitis	27.8	50.0	61.1	27.8	38.9	0.0	50.0	22.2	22.2	18
Not yet confirmed	27.5	29.4	33.3	19.6	43.1	11.8	52.9	35.3	23.5	51
Other	22.2	22.2	11.1	11.1	50.0	5.6	38.9	33.3	22.2	18



Section B : Health Care



Q6: How many surgical operations have you had for IBD and IBD-related medical problems?



	% 0 (None)	% 1	% 2	% 3	% 4	% 5 - 10	% More than 10	Resps
EFCCA Overall	60	16	8	5	4	5	2	4639

Gender	% 0 (None)	% 1	% 2	% 3	% 4	% 5 - 10	% More than 10	Resps
Male	59	16	8	6	4	5	2	1543
Female	60	15	8	5	3	5	2	3080
Not Stated	44	13	6	13	19	6	0	16



Q6: How many surgical operations have you had for IBD and IBD-related medical problems?

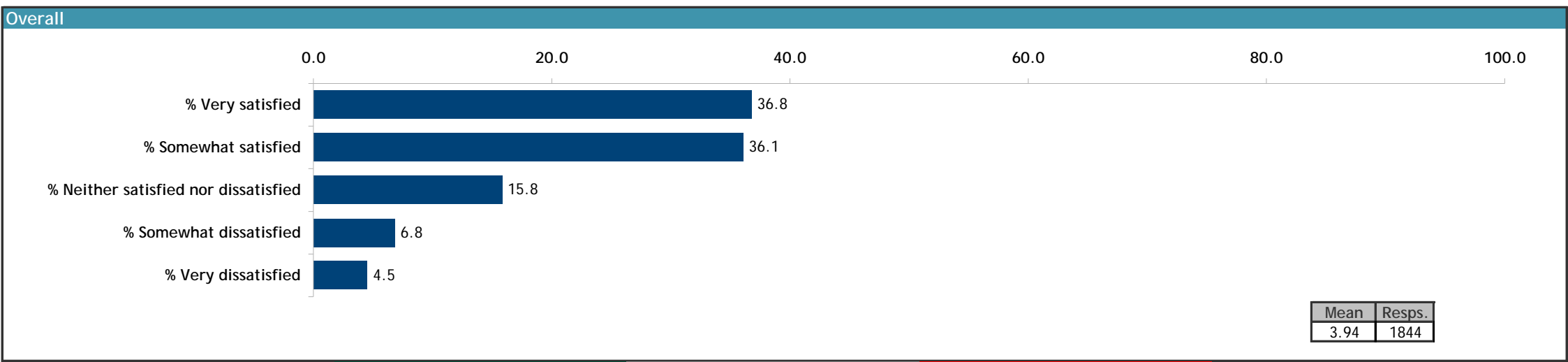
Age Group	% 0 (None)	% 1	% 2	% 3	% 4	% 5 - 10	% More than 10	Resps
<18 yrs	76	10	7	4	1	1	1	162
19-34	64	15	8	5	3	4	1	1994
35-54	55	17	9	5	4	6	3	2011
55+	55	15	6	7	6	7	3	464

Employment and Disability Status	% 0 (None)	% 1	% 2	% 3	% 4	% 5 - 10	% More than 10	Resps
Fully employed	63	16	8	4	3	3	1	2214
Under-employed due to IBD	49	18	10	7	5	8	3	459
Un-employed due to IBD	54	15	9	7	4	9	3	386
Student	70	14	7	4	1	3	1	670
Retired	42	18	7	8	5	12	7	257
Disabled	34	17	10	10	9	14	7	649
Seeking disability	50	17	11	8	3	8	2	183
Unable to receive disability status	52	17	11	7	3	8	3	324
Other	61	16	9	5	3	4	2	459
N/A	69	13	4	5	4	4	1	193

Type of IBD	% 0 (None)	% 1	% 2	% 3	% 4	% 5 - 10	% More than 10	Resps
Ulcerative colitis	87	5	3	2	1	1	0	1528
Crohn's Disease	44	22	11	7	5	8	3	2905
Indeterminate Colitis	79	7	3	4	4	3	0	107
Microscopic/collagenous colitis	94	0	0	6	0	0	0	18
Not yet confirmed	82	10	4	0	4	0	0	50
Other	76	12	0	6	6	0	0	17



Q7: How satisfied are you with the outcomes of your operation(s)?



	% Satisfied	% Neither	% Dissatisfied	Mean	% Diff v. Overall	Resps	NA
EFCCA Overall	73	16	11	3.94		1844	2106
Gender				Mean	% Diff v. Overall	Resps	NA
Male	73	16	10	3.96	+0.5	634	685
Female	72	16	12	3.92	-0.4	1201	1416
Not Stated	100			4.56	+15.7 ↑	9	5

Scale : 5 = Very satisfied, 4 = Somewhat satisfied, 3 = Neither satisfied nor dissatisfied, 2 = Somewhat dissatisfied, 1 = Very dissatisfied



Q7: How satisfied are you with the outcomes of your operation(s)?

Age Group	% Satisfied	% Neither	% Dissatisfied	Mean	% Diff v. Overall	Resps	NA
<18 yrs	74	16	11	3.92	-0.4	38	96
19-34	72	14	14	3.87	-1.7	712	1000
35-54	73	18	10	3.97	+0.9	890	826
55+	76	14	10	4.01	+1.8	201	179

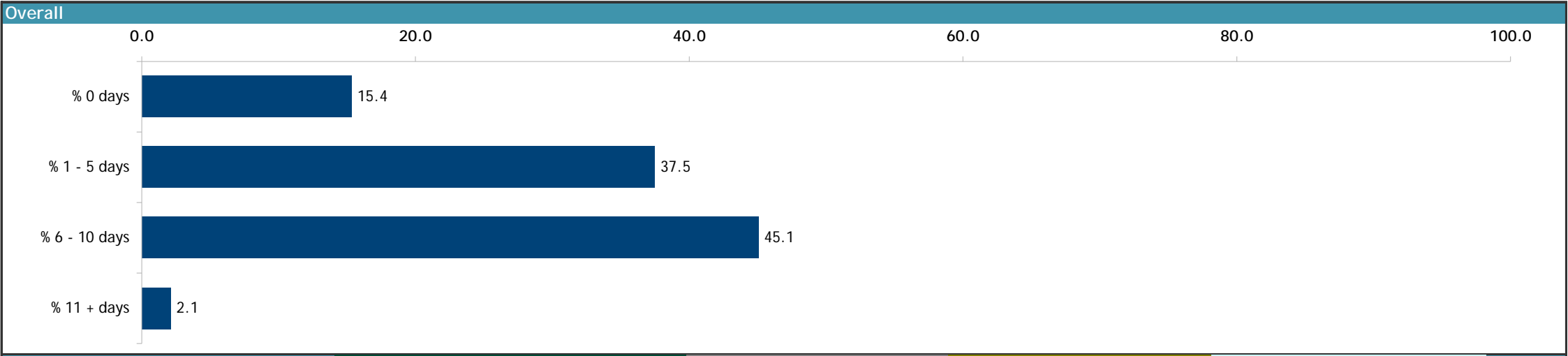
Employment and Disability Status	% Satisfied	% Neither	% Dissatisfied	Mean	% Diff v. Overall	Resps	NA
Fully employed	76	14	11	4.03	+2.3	805	1068
Under-employed due to IBD	65	18	17	3.70	-6.1 ↓	229	174
Un-employed due to IBD	60	21	18	3.64	-7.5 ↓	177	159
Student	77	11	12	3.97	+0.8	204	366
Retired	74	18	8	3.92	-0.5	145	73
Disabled	68	20	11	3.80	-3.4	421	155
Seeking disability	65	19	16	3.78	-4.1	89	61
Unable to receive disability status	70	17	13	3.80	-3.5	151	134
Other	72	20	8	4.02	+2.1	181	215
N/A	73	15	12	3.95	+0.3	60	103

Type of IBD	% Satisfied	% Neither	% Dissatisfied	Mean	% Diff v. Overall	Resps	NA
Ulcerative colitis	72	17	11	3.99	+1.3	205	990
Crohn's Disease	73	16	11	3.94	+0.0	1594	987
Indeterminate Colitis	57	26	17	3.65	-7.2 ↓	23	65
Microscopic/collagenous colitis	100	0	0	5.00	+27.0 ↑	1	14
Not yet confirmed	50	20	30	3.30	-16.2 ↓	10	36
Other	50	25	25	3.25	-17.5 ↓	4	10

Scale : 5 = Very satisfied, 4 = Somewhat satisfied, 3 = Neither satisfied nor dissatisfied, 2 = Somewhat dissatisfied, 1 = Very dissatisfied



Q8: Over the last 5 years, how many days in total have you been hospitalised because of IBD symptoms? (please type in number of days)



	% 0 days	% 1 - 5 days	% 6 - 10 days	% 11 + days	Resps
EFCCA Overall	15	37	45	2	4670

Gender	% 0 days	% 1 - 5 days	% 6 - 10 days	% 11 + days	Resps
Male	15	39	44	2	1549
Female	15	37	46	2	3093
Not Stated	50	32	18	0	28



Q8: Over the last 5 years, how many days in total have you been hospitalised because of IBD symptoms? (please type in number of days)

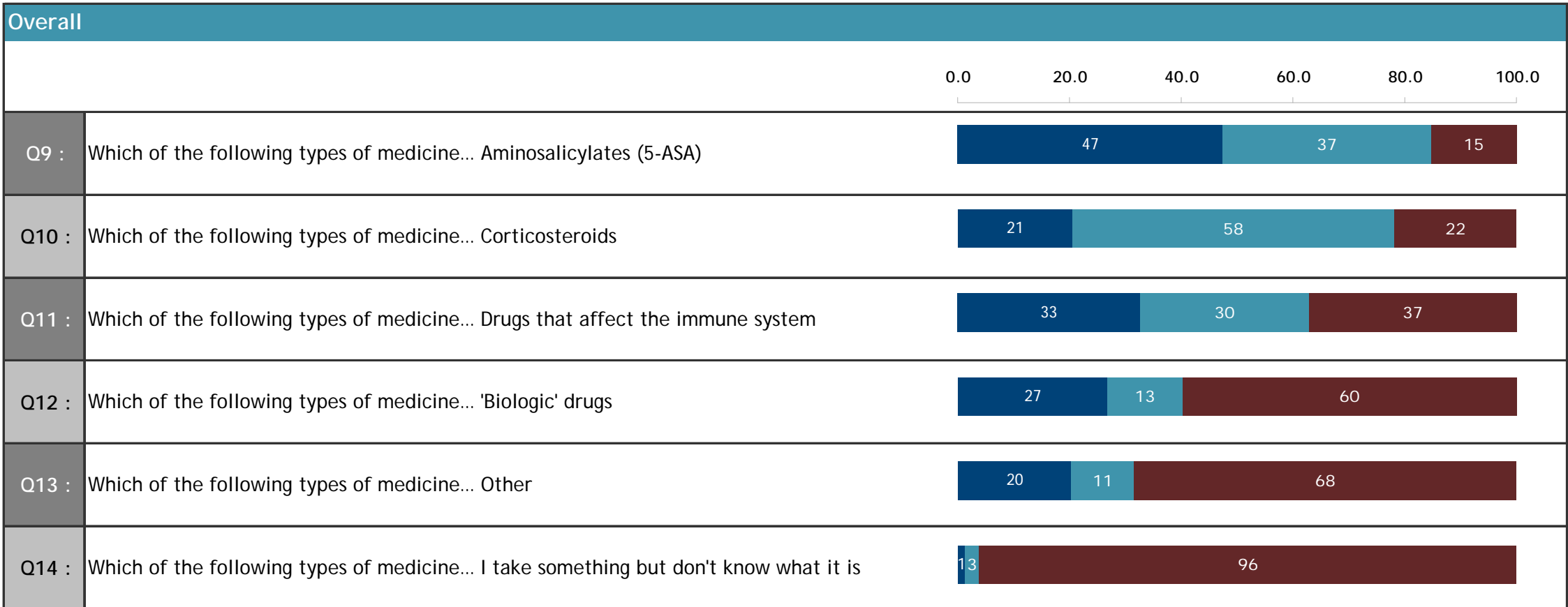
Age Group	% 0 days	% 1 - 5 days	% 6 - 10 days	% 11 + days	Resps
<18 yrs	18	23	59	1	163
19-34	14	34	50	1	2000
35-54	15	42	41	3	2020
55+	18	40	38	3	467

Employment and Disability Status	% 0 days	% 1 - 5 days	% 6 - 10 days	% 11 + days	Resps
Fully employed	16	35	48	1	2223
Under-employed due to IBD	12	47	38	3	459
Un-employed due to IBD	13	43	41	3	387
Student	15	30	54	1	673
Retired	15	50	28	7	258
Disabled	11	58	24	7	651
Seeking disability	18	47	33	3	184
Unable to receive disability status	12	44	41	3	324
Other	14	37	47	2	461
N/A	16	30	53	1	195

Type of IBD	% 0 days	% 1 - 5 days	% 6 - 10 days	% 11 + days	Resps
Ulcerative colitis	22	13	64	0	1535
Crohn's Disease	11	52	34	3	2914
Indeterminate Colitis	19	21	60	0	108
Microscopic/collagenous colitis	17	6	78	0	18
Not yet confirmed	10	16	71	4	51
Other	22	22	56	0	18



Overall summary: the types of medicine that are being taken right now or have been taken in the past?



* We assume a non-answer to this question means that the respondent has not knowingly taken this group of medication.

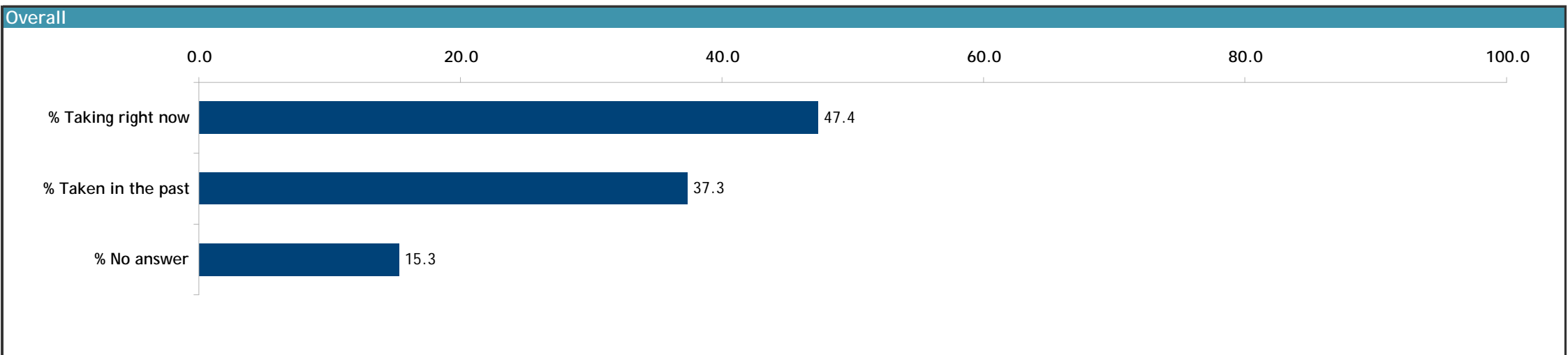
% Taking right now

% Taken in the past

% No answer



Q9: Which of the following types of medicine... Aminosalicylates (5-ASA)



	% Taking right now	% Taken in the past	% No answer	Resps
EFCCA Overall	47	37	15	4670

Gender	% Taking right now	% Taken in the past	% No answer	Resps
Male	51	36	13	1549
Female	46	38	16	3093
Not Stated	32	11	57	28

* We assume a non-answer to this question means that the respondent has not knowingly taken this group of medication.



Q9: Which of the following types of medicine... Aminosalicylates (5-ASA)

Age Group	% Taking right now	% Taken in the past	% No answer	Resps
<18 yrs	47	27	26	163
19-34	45	39	17	2000
35-54	49	38	12	2020
55+	51	33	16	467

Employment and Disability Status	% Taking right now	% Taken in the past	% No answer	Resps
Fully employed	51	35	14	2223
Under-employed due to IBD	43	42	15	459
Un-employed due to IBD	40	46	15	387
Student	46	33	20	673
Retired	46	37	17	258
Disabled	33	55	11	651
Seeking disability	47	40	13	184
Unable to receive disability status	46	37	16	324
Other	47	38	15	461
N/A	52	32	16	195

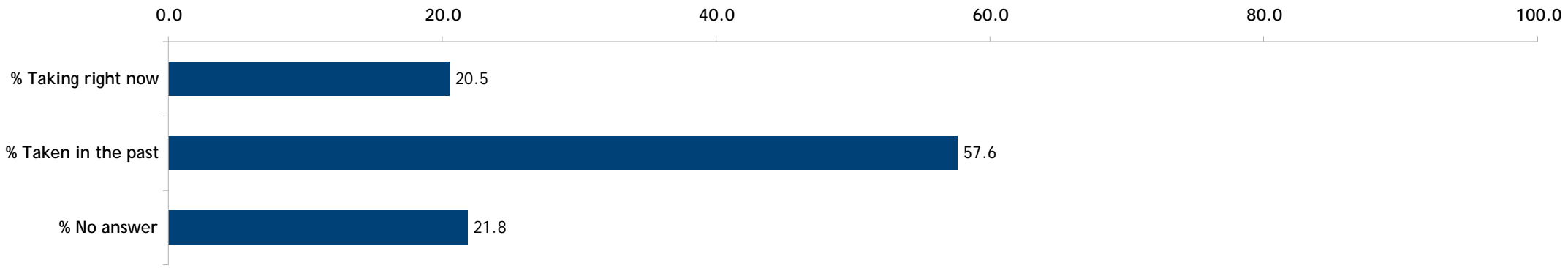
Type of IBD	% Taking right now	% Taken in the past	% No answer	Resps
Ulcerative colitis	72	23	5	1535
Crohn's Disease	35	46	19	2914
Indeterminate Colitis	61	31	8	108
Microscopic/collagenous colitis	33	22	44	18
Not yet confirmed	39	18	43	51
Other	17	22	61	18

* We assume a non-answer to this question means that the respondent has not knowingly taken this group of medication.



Q10: Which of the following types of medicine... Corticosteroids

Overall



	% Taking right now	% Taken in the past	% No answer	Resps
EFCCA Overall	21	58	22	4670
Gender				
Male	20	56	24	1549
Female	21	59	21	3093
Not Stated	18	14	68	28

* We assume a non-answer to this question means that the respondent has not knowingly taken this group of medication.



Q10: Which of the following types of medicine... Corticosteroids

Age Group	% Taking right now	% Taken in the past	% No answer	Resps
<18 yrs	23	44	33	163
19-34	22	61	17	2000
35-54	19	59	21	2020
55+	20	44	36	467

Employment and Disability Status	% Taking right now	% Taken in the past	% No answer	Resps
Fully employed	18	60	22	2223
Under-employed due to IBD	22	61	17	459
Un-employed due to IBD	27	58	16	387
Student	22	59	19	673
Retired	18	46	36	258
Disabled	24	62	14	651
Seeking disability	26	58	16	184
Unable to receive disability status	22	56	23	324
Other	19	59	23	461
N/A	18	49	33	195

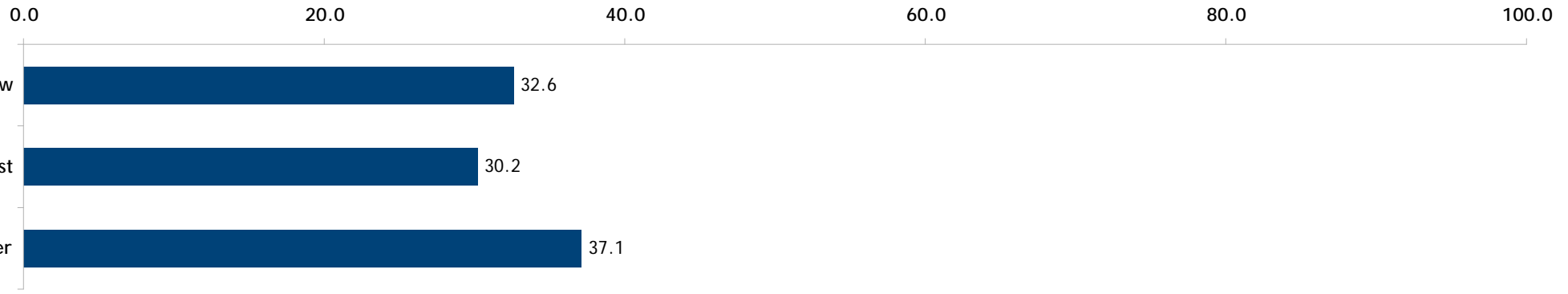
Type of IBD	% Taking right now	% Taken in the past	% No answer	Resps
Ulcerative colitis	25	55	21	1535
Crohn's Disease	18	61	21	2914
Indeterminate Colitis	18	52	31	108
Microscopic/collagenous colitis	28	50	22	18
Not yet confirmed	27	20	53	51
Other	11	22	67	18

* We assume a non-answer to this question means that the respondent has not knowingly taken this group of medication.



Q11: Which of the following types of medicine... Drugs that affect the immune system

Overall



	% Taking right now	% Taken in the past	% No answer	Resps
EFCCA Overall	33	30	37	4670
Gender				Resps
Male	31	30	39	1549
Female	33	30	36	3093
Not Stated	18	18	64	28

* We assume a non-answer to this question means that the respondent has not knowingly taken this group of medication.



Q11: Which of the following types of medicine... Drugs that affect the immune system

Age Group	% Taking right now	% Taken in the past	% No answer	Resps
<18 yrs	46	28	26	163
19-34	36	32	32	2000
35-54	31	30	39	2020
55+	24	24	52	467

Employment and Disability Status	% Taking right now	% Taken in the past	% No answer	Resps
Fully employed	31	29	40	2223
Under-employed due to IBD	38	31	31	459
Un-employed due to IBD	36	39	25	387
Student	40	30	29	673
Retired	22	27	51	258
Disabled	31	45	24	651
Seeking disability	33	35	32	184
Unable to receive disability status	35	32	33	324
Other	32	30	38	461
N/A	32	24	44	195

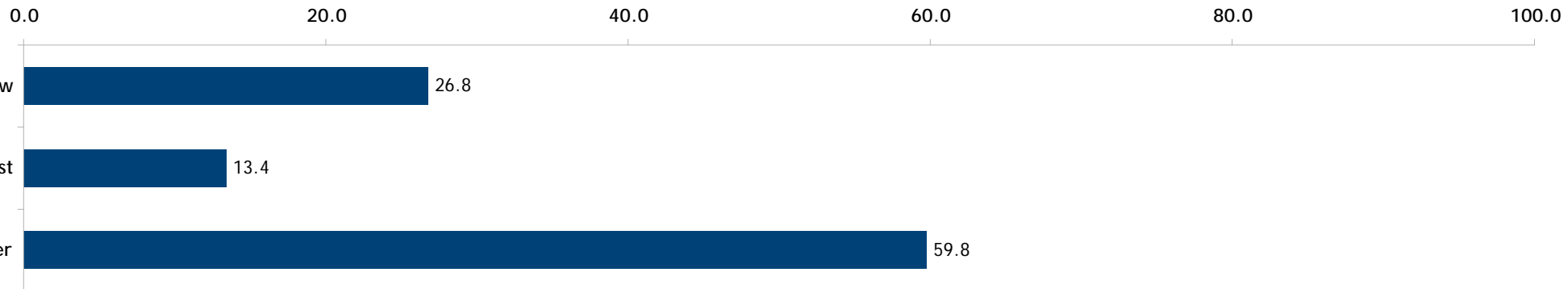
Type of IBD	% Taking right now	% Taken in the past	% No answer	Resps
Ulcerative colitis	27	24	49	1535
Crohn's Disease	36	35	29	2914
Indeterminate Colitis	31	32	37	108
Microscopic/collagenous colitis			100	18
Not yet confirmed	12	8	80	51
Other	22	11	67	18

* We assume a non-answer to this question means that the respondent has not knowingly taken this group of medication.



Q12: Which of the following types of medicine... 'Biologic' drugs

Overall



	% Taking right now	% Taken in the past	% No answer	Resps
EFCCA Overall	27	13	60	4670

Gender

Gender	% Taking right now	% Taken in the past	% No answer	Resps
Male	28	14	59	1549
Female	27	13	60	3093
Not Stated	7	7	86	28

* We assume a non-answer to this question means that the respondent has not knowingly taken this group of medication.



Q12: Which of the following types of medicine... 'Biologic' drugs

Age Group	% Taking right now		% Taken in the past	% No answer	Resps
<18 yrs	23	15		63	163
19-34	31	14		55	2000
35-54	25	14		61	2020
55+	18	10		72	467

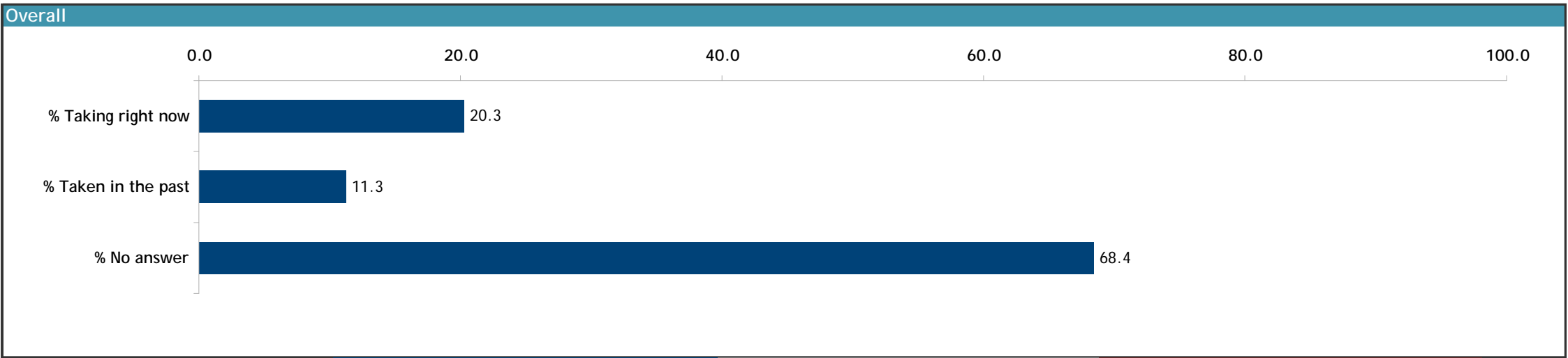
Employment and Disability Status	% Taking right now		% Taken in the past	% No answer	Resps
Fully employed	26	12		62	2223
Under-employed due to IBD	29	16		55	459
Un-employed due to IBD	34	15		51	387
Student	28	13		59	673
Retired	24	10		65	258
Disabled	40	22		38	651
Seeking disability	34	17		49	184
Unable to receive disability status	26	15		60	324
Other	24	14		62	461
N/A	18	13		69	195

Type of IBD	% Taking right now		% Taken in the past	% No answer	Resps
Ulcerative colitis	12	11		76	1535
Crohn's Disease	36	15		50	2914
Indeterminate Colitis	20	15		65	108
Microscopic/collagenous colitis	6			94	18
Not yet confirmed	2	4		94	51
Other	11			89	18

* We assume a non-answer to this question means that the respondent has not knowingly taken this group of medication.



Q13: Which of the following types of medicine... Other



	% Taking right now	% Taken in the past	% No answer	Resps
EFCCA Overall	20	11	68	4670

Gender	% Taking right now	% Taken in the past	% No answer	Resps
Male	20	11	68	1549
Female	20	11	68	3093
Not Stated	14	7	79	28

* We assume a non-answer to this question means that the respondent has not knowingly taken this group of medication.



Q13: Which of the following types of medicine... Other

Age Group	% Taking right now		% Taken in the past	% No answer	Resps
<18 yrs	29	7	64		163
19-34	20	13	67		2000
35-54	20	10	70		2020
55+	20	9	71		467

Employment and Disability Status	% Taking right now		% Taken in the past	% No answer	Resps
Fully employed	17	11	72		2223
Under-employed due to IBD	25	9	66		459
Un-employed due to IBD	27	11	61		387
Student	21	12	67		673
Retired	25	11	64		258
Disabled	33	14	53		651
Seeking disability	24	14	62		184
Unable to receive disability status	23	14	63		324
Other	22	13	65		461
N/A	16	10	74		195

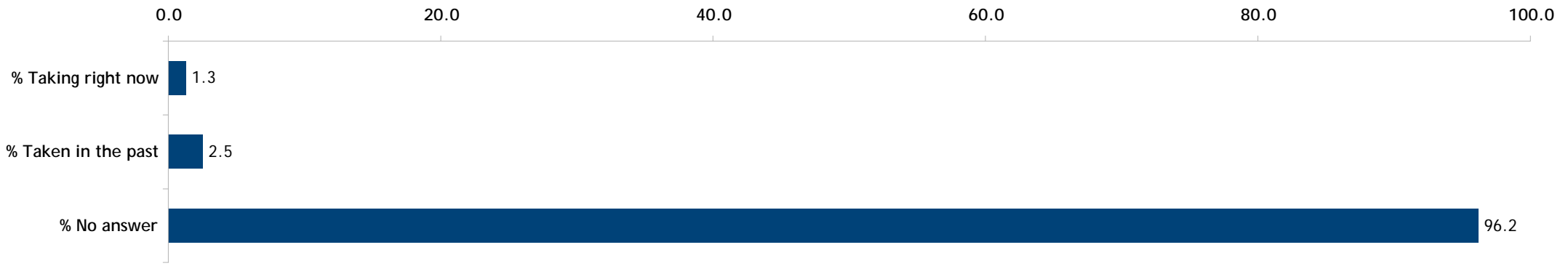
Type of IBD	% Taking right now		% Taken in the past	% No answer	Resps
Ulcerative colitis	17	10	74		1535
Crohn's Disease	22	12	66		2914
Indeterminate Colitis	20	9	70		108
Microscopic/collagenous colitis	17	28	56		18
Not yet confirmed	25	14	61		51
Other	39	17	44		18

* We assume a non-answer to this question means that the respondent has not knowingly taken this group of medication.



Q14: Which of the following types of medicine... I take something but don't know what it is

Overall



	% Taking right now	% Taken in the past	% No answer	Resps
EFCCA Overall	1.3	2.5	96.2	4670

Gender

Gender	% Taking right now	% Taken in the past	% No answer	Resps
Male	1.3	2.5	96.2	1549
Female	1.2	2.5	96.3	3093
Not Stated	4.0	0.0	96.0	28

* We assume a non-answer to this question means that the respondent has not knowingly taken this group of medication.



Q14: Which of the following types of medicine... I take something but don't know what it is

Age Group	% Taking right now	% Taken in the past	% No answer	Resps
<18 yrs	4 1	94		163
19-34	1 3	96		2000
35-54	1 2	97		2020
55+	1 2	97		467

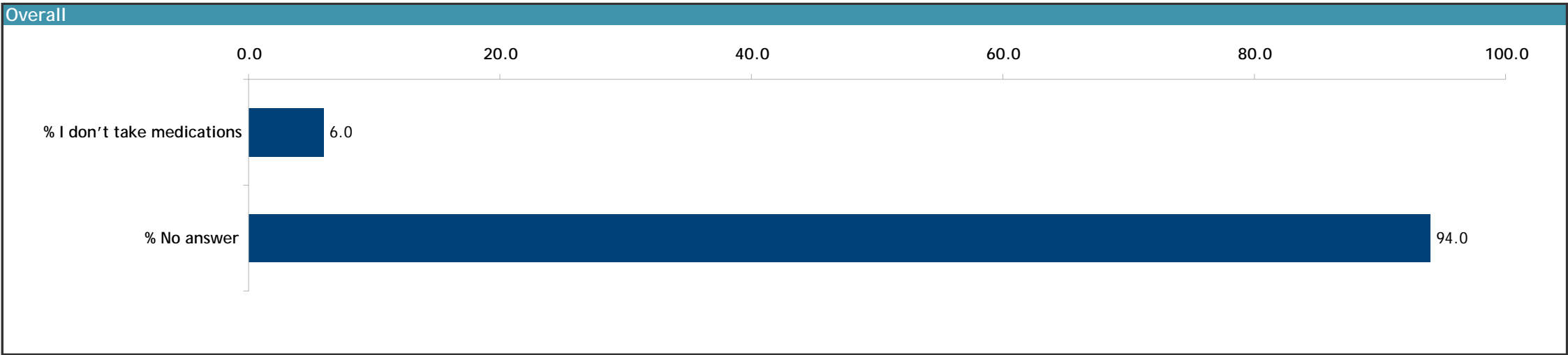
Employment and Disability Status				Resps
Fully employed	2		97	2223
Under-employed due to IBD	2 3		95	459
Un-employed due to IBD	3 4		94	387
Student	1 3		95	673
Retired	1 2		97	258
Disabled	1 3		96	651
Seeking disability	4 4		92	184
Unable to receive disability status	3 3		94	324
Other	1 3		96	461
N/A	2 3		96	195

Type of IBD				Resps
Ulcerative colitis	3		96	1535
Crohn's Disease	1 2		96	2914
Indeterminate Colitis	4 1		95	108
Microscopic/collagenous colitis			100	18
Not yet confirmed	4 4		92	51
Other	6		94	18

* We assume a non-answer to this question means that the respondent has not knowingly taken this group of medication.



Q15: Which of the following types of medicine... I don't take any medications



	% I don't take medications	% No answer	% Don't take medication	Resps
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EFCCA Overall	6	94	6.0	2987
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Gender				% Don't take medication	Resps
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Male	7	93	6.8	1023
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Female	5	95	5.4	1945
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Not Stated	16	84	15.8	19
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Q15: Which of the following types of medicine... I don't take any medications

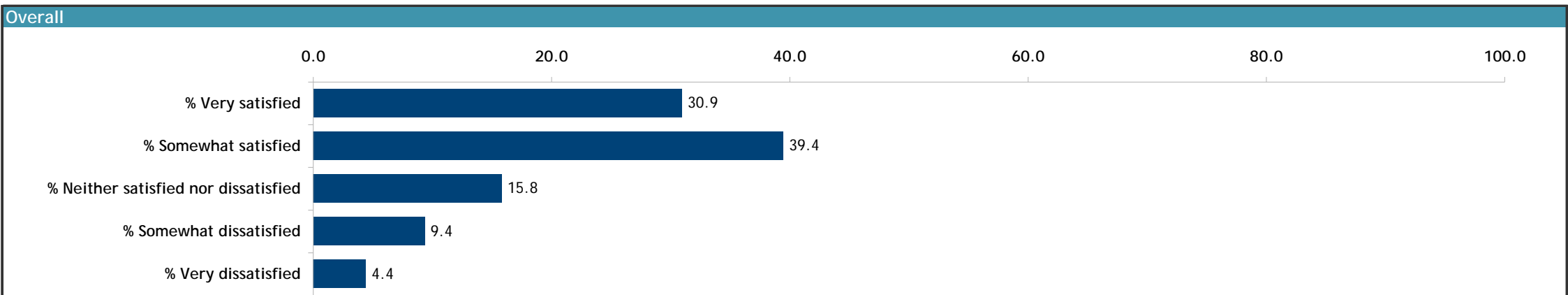
Age Group	% I don't take medications	% No answer	% Don't take medication	Resps
<18 yrs	6	94	6.3	96
19-34	6	94	5.8	1296
35-54	6	94	6.2	1276
55+	5	95	5.3	304

Employment and Disability Status	% I don't take medications	% No answer	% Don't take medication	Resps
Fully employed	5	95	5.4	1528
Under-employed due to IBD	9	91	9.5	253
Un-employed due to IBD	6	94	5.9	253
Student	5	95	5.4	441
Retired	7	93	6.8	162
Disabled	8	92	8.1	395
Seeking disability	6	94	5.7	123
Unable to receive disability status	4	96	3.5	198
Other	7	93	6.8	278
N/A	12	88	11.6	129

Type of IBD	% I don't take medications	% No answer	% Don't take medication	Resps
Ulcerative colitis	5	95	5.4	1017
Crohn's Disease	6	94	6.0	1826
Indeterminate Colitis	5	95	5.5	73
Microscopic/collagenous colitis	13	88	12.5	8
Not yet confirmed	18	83	17.5	40
Other	13	88	12.5	8



Q16: Overall, how satisfied are you with your current treatment plan for IBD?



Mean	Resps.
3.83	3701

	% Satisfied	% Neither	% Dissatisfied	Mean	% Diff v. Overall	Resps	NA
EFCCA Overall	70	16	14	3.83		3701	0
Gender				Mean	% Diff v. Overall	Resps	NA
Male	72	15	12	3.86	+0.9	1226	0
Female	69	16	14	3.81	-0.5	2466	0
Not Stated	67	33	0	4.11	+7.3 ↑	9	0

Scale : 5 = Very satisfied, 4 = Somewhat satisfied, 3 = Neither satisfied nor dissatisfied, 2 = Somewhat dissatisfied, 1 = Very dissatisfied



Q16: Overall, how satisfied are you with your current treatment plan for IBD?

Age Group	% Satisfied	% Neither	% Dissatisfied	Mean	% Diff v. Overall	Resps	NA
<18 yrs	75	9	16	3.87	+1.0	122	0
19-34	69	15	16	3.77	-1.6	1562	0
35-54	72	16	12	3.89	+1.5	1637	0
55+	69	19	13	3.83	+0.0	375	0

Employment and Disability Status	% Satisfied	% Neither	% Dissatisfied	Mean	% Diff v. Overall	Resps	NA
Fully employed	74	15	10	3.94	+2.9	1770	0
Under-employed due to IBD	63	17	20	3.57	-6.8 ↓	368	0
Un-employed due to IBD	57	14	29	3.38	-11.7 ↓	297	0
Student	71	15	14	3.81	-0.4	512	0
Retired	70	16	14	3.85	+0.4	208	0
Disabled	69	17	14	3.82	-0.2	541	0
Seeking disability	56	18	26	3.45	-10.0 ↓	141	0
Unable to receive disability status	59	17	24	3.47	-9.5 ↓	241	0
Other	74	15	11	3.92	+2.3	377	0
N/A	64	22	14	3.75	-2.0	158	0

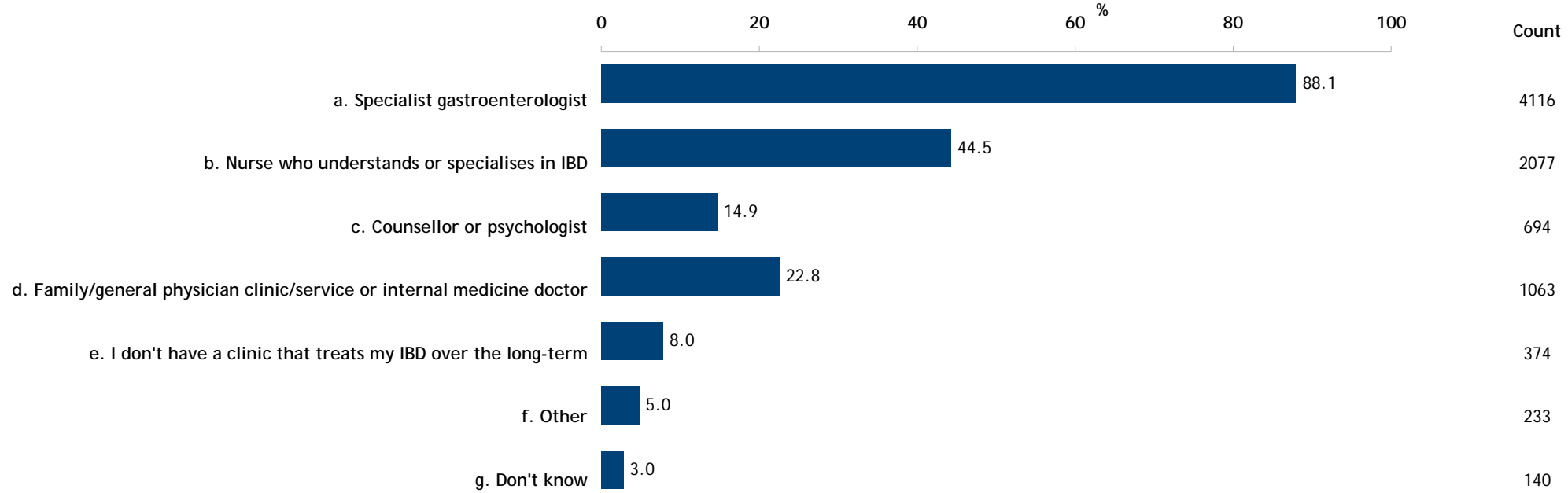
Type of IBD	% Satisfied	% Neither	% Dissatisfied	Mean	% Diff v. Overall	Resps	NA
Ulcerative colitis	67	18	15	3.76	-1.8	1236	0
Crohn's Disease	74	14	12	3.91	+2.0	2319	0
Indeterminate Colitis	57	14	29	3.40	-11.2 ↓	77	0
Microscopic/collagenous colitis	53	27	20	3.53	-7.8 ↓	15	0
Not yet confirmed	24	26	50	2.59	-32.4 ↓	34	0
Other	42	17	42	2.92	-23.9 ↓	12	0

Scale : 5 = Very satisfied, 4 = Somewhat satisfied, 3 = Neither satisfied nor dissatisfied, 2 = Somewhat dissatisfied, 1 = Very dissatisfied



About your experience with Health Care Professionals

Q17: As far as you are aware, which of the following types of healthcare professionals are available at the clinic that treats your IBD? (Tick all that apply)



Resps (4670)

About your experience with Health Care Professionals

Q17: As far as you are aware, which of the following types of healthcare professionals are available at the clinic that treats your IBD? (Tick all that apply)

Gender	a. Specialist gastroenterologist	b. Nurse who understands or specialises in IBD	c. Counsellor or psychologist	d. Family/general physician clinic/service or internal medicine doctor	e. I don't have a clinic that treats my IBD over the long-term	f. Other	g. Don't know	Resps
Male	89.5	42.6	15.6	23.2	7.3	5.4	3.1	1549
Female	87.8	45.7	14.6	22.6	8.4	4.8	2.9	3093
Not Stated	42.9	17.9	3.6	14.3	3.6	7.1	7.1	28

Age Group	a.	b.	c.	d.	e.	f.	g.	Resps
<18 yrs	92.0	46.6	35.6	19.6	3.7	7.4	3.7	163
19-34	88.5	47.3	15.9	22.7	7.4	4.8	3.6	2000
35-54	88.3	43.8	13.6	23.3	8.9	5.3	2.4	2020
55+	87.2	36.2	9.4	23.1	8.6	3.6	3.0	467



About your experience with Health Care Professionals

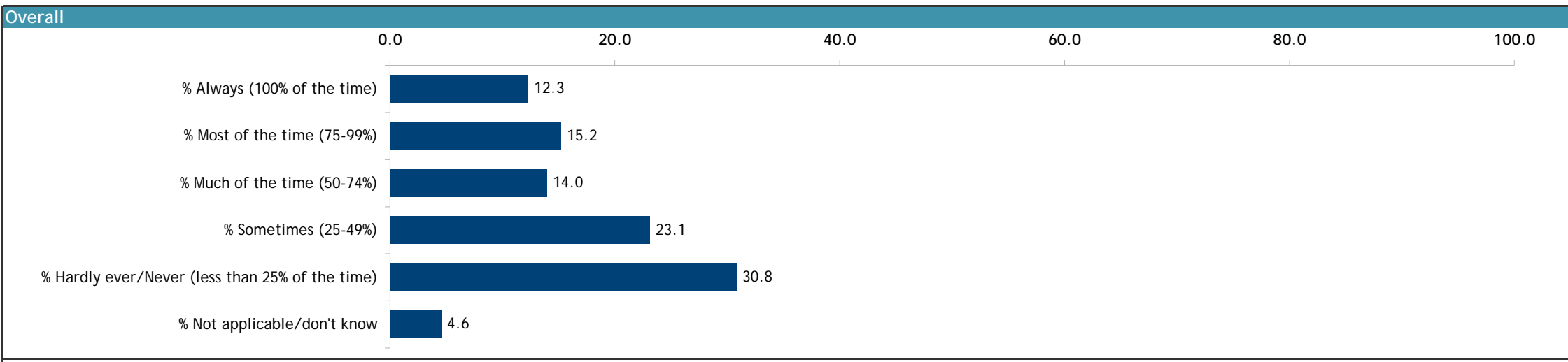
Q17: As far as you are aware, which of the following types of healthcare professionals are available at the clinic that treats your IBD? (Tick all that apply)

Employment and Disability Status	a. Specialist gastroenterologist	b. Nurse who understands or specialises in IBD	c. Counsellor or psychologist	d. Family/general physician clinic/service or internal medicine doctor	e. I don't have a clinic that treats my IBD over the long-term	f. Other	g. Don't know	Resps
Fully employed	88.9	44.1	12.6	20.3	7.9	4.5	2.7	2223
Under-employed due to IBD	86.9	50.1	17.9	27.5	7.2	6.3	3.1	459
Un-employed due to IBD	86.8	46.0	16.5	27.6	8.5	7.0	5.4	387
Student	91.1	48.1	22.0	22.7	5.9	5.6	3.3	673
Retired	91.5	38.8	12.4	30.6	8.9	3.1	2.3	258
Disabled	90.0	46.5	23.8	32.3	9.4	7.7	3.1	651
Seeking disability	88.6	42.9	14.7	29.3	9.8	4.9	3.8	184
Unable to receive disability status	80.9	45.1	13.6	26.5	12.7	7.1	2.2	324
Other	85.2	41.6	13.9	23.6	8.5	6.7	3.5	461
N/A	83.6	32.3	7.7	11.3	13.3	5.6	5.1	195

Type of IBD	a.	b.	c.	d.	e.	f.	g.	Resps
Ulcerative colitis	89.1	45.1	12.4	18.3	7.8	3.4	2.8	1535
Crohn's Disease	88.9	45.2	16.3	25.7	7.5	5.7	3.0	2914
Indeterminate Colitis	83.3	43.5	18.5	14.8	13.0	9.3	1.9	108
Microscopic/collagenous colitis	77.8	22.2	11.1	27.8	16.7	11.1	5.6	18
Not yet confirmed	64.7	23.5	3.9	11.8	23.5	5.9	7.8	51
Other	55.6	11.1	22.2	27.8	33.3	5.6	11.1	18



Q18: How often, after an appointment with a gastroenterologist do you wish that he or she should have asked you more probing questions to better understand your disease status?



	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
EFCCA Overall	12	15	14	23	31	5	4643

Gender	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
Male	14	15	15	21	30	5	1546
Female	12	15	13	24	31	4	3083
Not Stated	7	21	14	14	21	21	14



Q18: How often, after an appointment with a gastroenterologist do you wish that he or she should have asked you more probing questions to better understand your disease status?

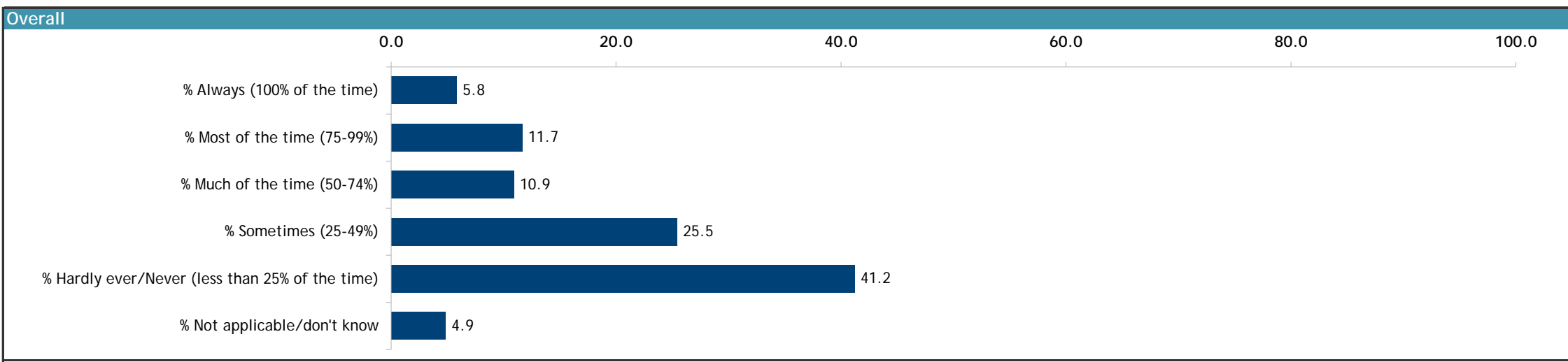
Age Group	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
<18 yrs	12	15	10	18	37	9	162
19-34	12	17	15	24	29	4	1998
35-54	12	14	14	24	32	4	2014
55+	15	15	13	16	33	7	462

Employment and Disability Status	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
Fully employed	11	15	14	24	32	4	2217
Under-employed due to IBD	12	20	16	23	26	4	457
Un-employed due to IBD	16	22	14	22	22	4	387
Student	12	16	14	22	31	5	672
Retired	14	16	11	18	32	10	257
Disabled	10	16	17	21	31	5	650
Seeking disability	18	18	15	26	20	2	182
Unable to receive disability status	16	16	17	24	23	3	322
Other	10	13	11	23	35	7	458
N/A	18	12	11	19	34	6	194

Type of IBD	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
Ulcerative colitis	12	16	15	24	29	4	1530
Crohn's Disease	12	14	14	23	32	5	2906
Indeterminate Colitis	21	19	11	25	19	5	108
Microscopic/collagenous colitis	22	22	11	22	11	11	18
Not yet confirmed	20	18	14	14	24	10	50
Other	24	24	12	18	6	18	17



Q19: How often, after an appointment with a gastroenterologist, do you feel you didn't get to tell the doctor something about your IBD that may have been important?



	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
EFCCA Overall	6	12	11	25	41	5	4616

Gender	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
Male	5	11	10	26	44	5	1533
Female	6	12	11	25	40	5	3070
Not Stated	8	23	15	23	23	8	13



Q19: How often, after an appointment with a gastroenterologist, do you feel you didn't get to tell the doctor something about your IBD that may have been important?

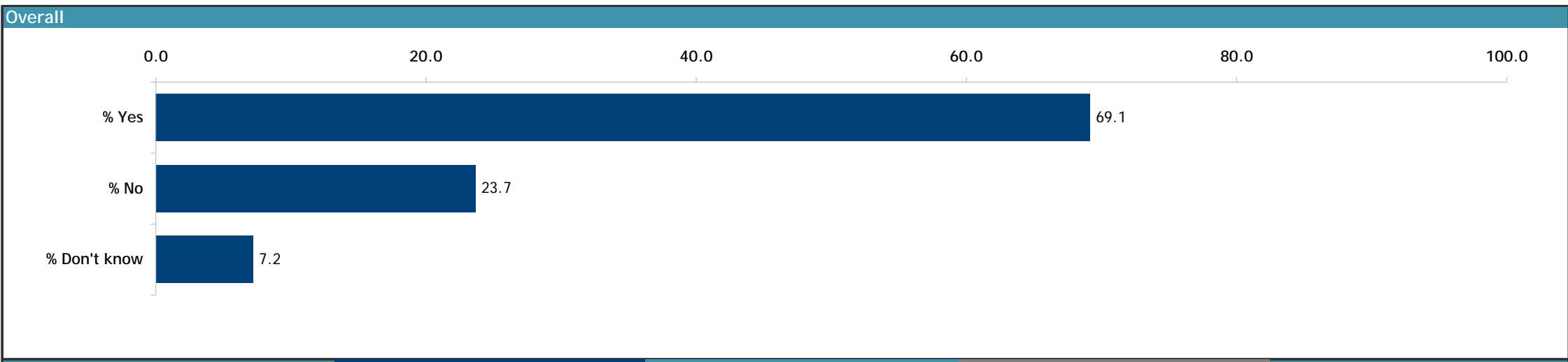
Age Group	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
<18 yrs	3	7	7	24	47	11	162
19-34	6	13	11	26	40	4	1994
35-54	6	11	11	25	42	5	1998
55+	6	10	11	23	42	7	455

Employment and Disability Status	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
Fully employed	5	11	11	25	44	4	2207
Under-employed due to IBD	9	15	13	27	31	5	452
Un-employed due to IBD	9	19	15	25	30	3	384
Student	5	11	9	27	42	6	671
Retired	5	6	9	25	45	9	249
Disabled	5	12	12	24	43	4	644
Seeking disability	9	14	11	29	33	3	180
Unable to receive disability status	10	15	15	26	30	3	317
Other	4	8	11	28	43	6	458
N/A	6	14	8	21	44	7	194

Type of IBD	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
Ulcerative colitis	6	12	11	26	40	4	1517
Crohn's Disease	5	11	10	25	43	5	2893
Indeterminate Colitis	13	16	17	23	27	5	108
Microscopic/collagenous colitis	17	6	6	39	6	28	18
Not yet confirmed	16	12	16	22	24	10	50
Other	12	12	18	29	12	18	17



Q20: Do you believe that you have adequate access to your IBD professional? For example, can you get an appointment to see your IBD health care professional on a timely basis?



	% Yes	% No	% Don't know	% Yes	Resps
EFCCA Overall	69	24	7	69.1	4645

Gender	% Yes	Resps
Male	71.7	1547
Female	67.9	3084
Not Stated	64.3	14

Scale : 3 = Yes, 2 = No, 1 = Don't know



Q20: Do you believe that you have adequate access to your IBD professional? For example, can you get an appointment to see your IBD health care professional on a timely basis?

Age Group	% Yes	% No	% Don't know	% Yes	Resps
<18 yrs	80	15	5	79.6	162
19-34	67	26	7	67.1	1999
35-54	71	22	7	70.9	2012
55+	67	24	9	66.5	466

Employment and Disability Status	% Yes	% No	% Don't know	% Yes	Resps
Fully employed	71	22	7	70.5	2218
Under-employed due to IBD	61	31	7	61.1	458
Un-employed due to IBD	62	31	7	61.8	387
Student	70	24	6	69.6	672
Retired	74	17	9	73.9	257
Disabled	75	22	4	74.5	651
Seeking disability	67	27	5	67.0	182
Unable to receive disability status	56	37	7	55.9	324
Other	70	21	8	70.2	459
N/A	65	21	13	65.5	194

Type of IBD	% Yes	% No	% Don't know	% Yes	Resps
Ulcerative colitis	68	23	8	68.4	1531
Crohn's Disease	71	23	6	71.0	2906
Indeterminate Colitis	53	41	6	52.8	108
Microscopic/collagenous colitis	56	33	11	55.6	18
Not yet confirmed	36	48	16	36.0	50
Other	28	33	39	27.8	18

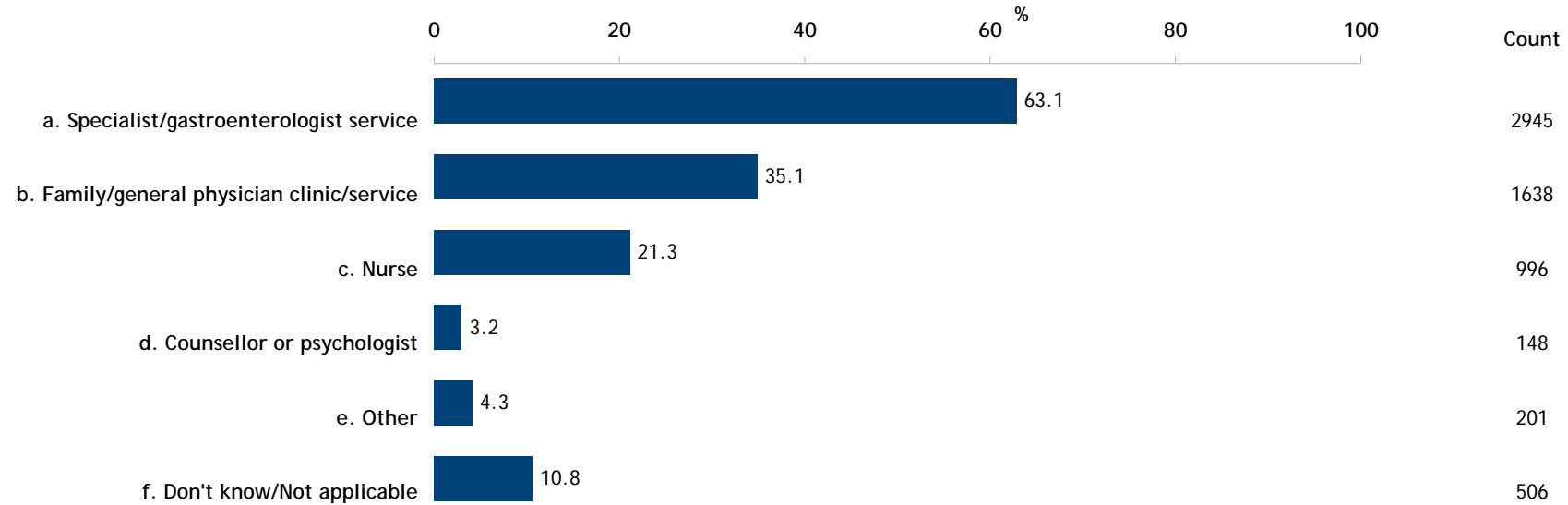
Scale : 3 = Yes, 2 = No, 1 = Don't know



Please tick your answer to the following questions about your health care team as appropriate

Q21:

Which professional(s) provides the best range of options to communicate with them (eg telephone, email, drop-in clinic without appointments)? (Tick all that apply)



Resps (4670)



Please tick your answer to the following questions about your health care team as appropriate

Q21: Which professional(s) provides the best range of options to communicate with them (eg telephone, email, drop-in clinic without appointments)? (Tick all that apply)

Gender	a. Specialist/gastroenterologist service	b. Family/general physician clinic/service	c. Nurse	d. Counsellor or psychologist	e. Other	f. Don't know/Not applicable	Resps
Male	67.0	32.1	17.8	2.3	4.8	9.9	1549
Female	61.4	36.7	23.2	3.6	4.1	11.3	3093
Not Stated	28.6	17.9	14.3	0.0	0.0	7.1	28

Age Group	a.	b.	c.	d.	e.	f.	Resps
<18 yrs	74.2	30.7	20.9	6.1	5.5	5.5	163
19-34	59.6	35.1	24.0	3.6	4.8	11.3	2000
35-54	65.4	35.3	20.0	2.9	4.2	11.0	2020
55+	65.5	36.4	16.7	1.7	2.4	10.5	467



Please tick your answer to the following questions about your health care team as appropriate

Q21: Which professional(s) provides the best range of options to communicate with them (eg telephone, email, drop-in clinic without appointments)? (Tick all that apply)

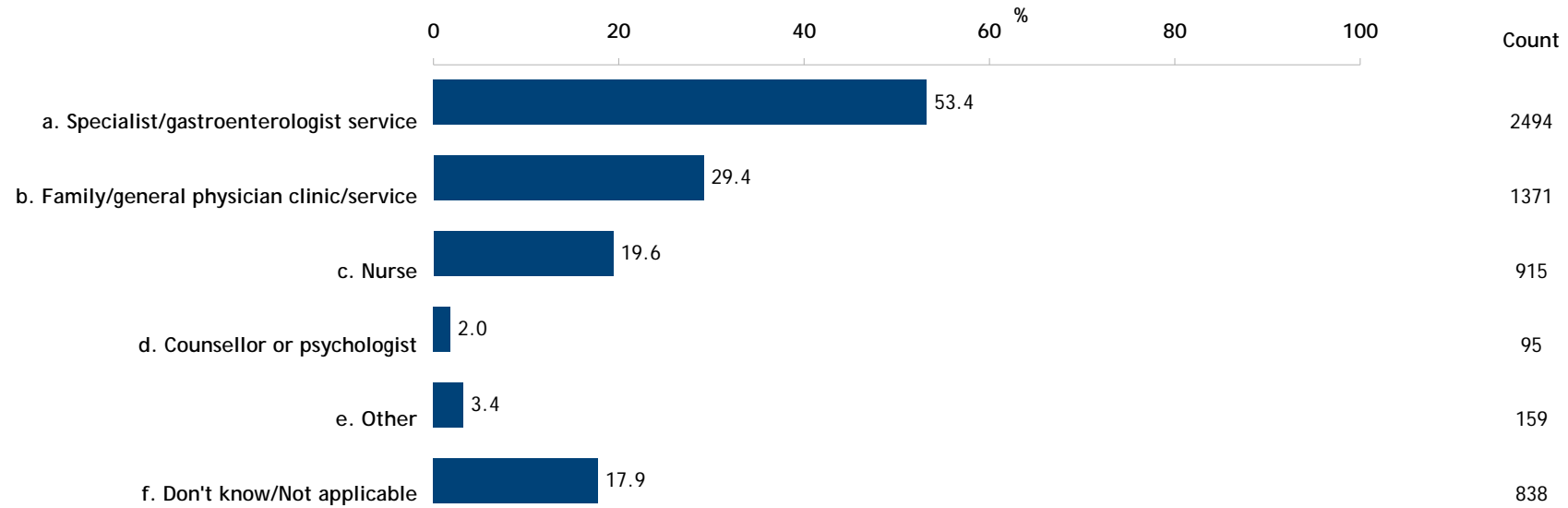
Employment and Disability Status	a. Specialist/gastroenterologist service	b. Family/general physician clinic/service	c. Nurse	d. Counsellor or psychologist	e. Other	f. Don't know/Not applicable	Resps
Fully employed	63.7	32.3	21.4	2.1	3.7	10.9	2223
Under-employed due to IBD	57.5	40.5	24.6	5.0	4.1	10.7	459
Un-employed due to IBD	56.6	42.1	24.3	4.9	7.2	11.9	387
Student	63.3	33.4	24.2	5.2	5.5	9.5	673
Retired	72.1	36.4	15.5	2.3	4.3	7.4	258
Disabled	72.2	43.3	18.4	5.2	7.8	8.0	651
Seeking disability	66.3	33.7	19.6	5.4	5.4	11.4	184
Unable to receive disability status	52.8	40.1	20.7	3.4	6.2	11.1	324
Other	61.4	37.7	20.2	4.6	6.1	12.1	461
N/A	61.5	27.2	9.7	2.1	6.7	18.5	195

Type of IBD	a.	b.	c.	d.	e.	f.	Resps
Ulcerative colitis	59.9	30.9	24.0	2.5	3.7	11.4	1535
Crohn's Disease	66.2	37.3	20.0	3.5	4.5	10.0	2914
Indeterminate Colitis	50.9	34.3	29.6	3.7	2.8	15.7	108
Microscopic/collagenous colitis	33.3	44.4	0.0	16.7	22.2	27.8	18
Not yet confirmed	31.4	37.3	17.6	0.0	5.9	25.5	51
Other	38.9	44.4	5.6	5.6	11.1	11.1	18



Q22:

Which professional(s) is best at returning your calls promptly? (Tick all that apply)



Resps (4670)



Q22: Which professional(s) is best at returning your calls promptly? (Tick all that apply)

Gender	a. Specialist/gastroenterologist service	b. Family/general physician clinic/service	c. Nurse	d. Counsellor or psychologist	e. Other	f. Don't know/Not applicable	Resps
Male	55.3	25.1	16.8	1.6	3.9	19.3	1549
Female	52.8	31.6	21.1	2.3	3.2	17.3	3093
Not Stated	14.3	17.9	10.7	0.0	3.6	17.9	28

Age Group	a.	b.	c.	d.	e.	f.	Resps
<18 yrs	65.6	29.4	19.6	6.1	4.9	9.2	163
19-34	51.5	28.5	21.9	2.6	4.0	18.9	2000
35-54	55.0	30.0	18.7	1.6	3.1	17.5	2020
55+	52.2	31.0	14.6	0.4	1.9	19.1	467



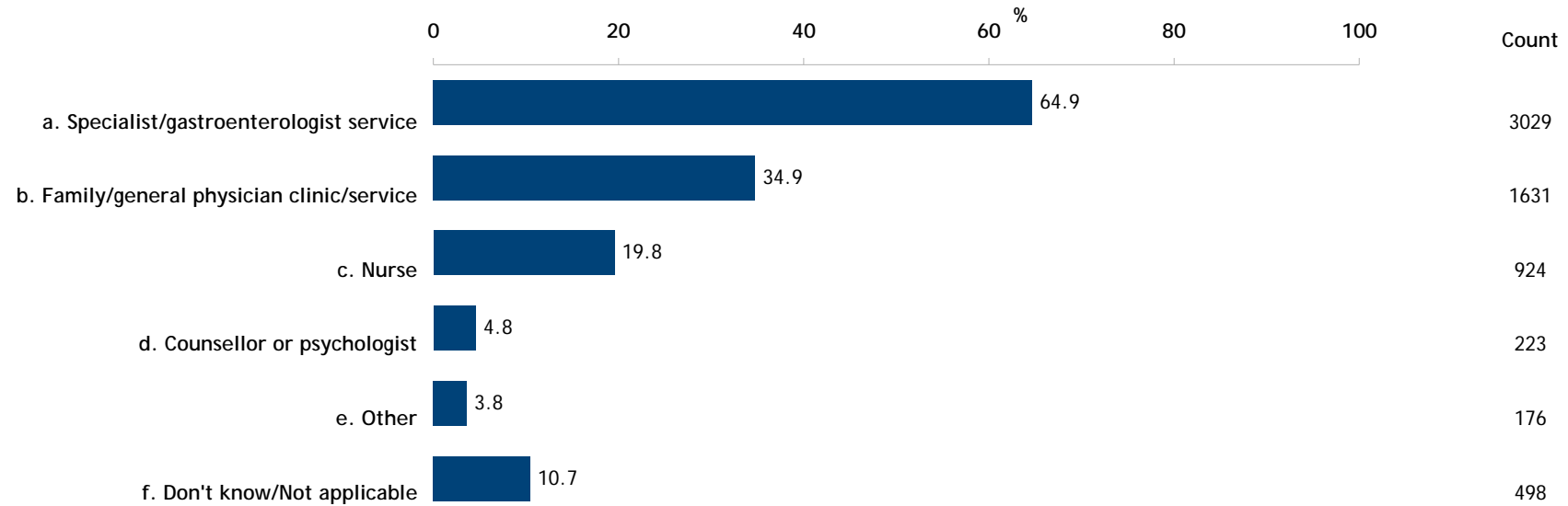
Q22: Which professional(s) is best at returning your calls promptly? (Tick all that apply)

Employment and Disability Status	a. Specialist/gastroenterologist service	b. Family/general physician clinic/service	c. Nurse	d. Counsellor or psychologist	e. Other	f. Don't know/Not applicable	Resps
Fully employed	53.6	26.3	19.5	1.0	3.0	18.9	2223
Under-employed due to IBD	50.3	35.9	22.4	2.4	4.6	15.0	459
Un-employed due to IBD	47.3	37.2	23.0	2.8	6.7	15.5	387
Student	55.3	26.4	23.0	4.6	4.8	16.9	673
Retired	60.5	31.4	14.3	1.9	2.7	16.3	258
Disabled	61.6	36.6	18.1	3.8	5.8	13.7	651
Seeking disability	60.9	28.8	19.6	4.9	5.4	14.7	184
Unable to receive disability status	43.8	32.4	18.2	2.5	5.6	21.0	324
Other	53.4	32.3	19.1	3.3	5.4	16.9	461
N/A	51.8	22.1	8.7	2.1	3.6	29.7	195

Type of IBD	a.	b.	c.	d.	e.	f.	Resps
Ulcerative colitis	50.3	24.2	21.2	1.7	2.3	21.2	1535
Crohn's Disease	56.5	32.0	19.1	2.2	3.8	15.7	2914
Indeterminate Colitis	39.8	28.7	24.1	1.9	4.6	25.0	108
Microscopic/collagenous colitis	38.9	55.6	0.0	11.1	22.2	16.7	18
Not yet confirmed	19.6	29.4	9.8	2.0	5.9	41.2	51
Other	38.9	38.9	0.0	5.6	5.6	11.1	18



Q23: Which professional(s) is best at giving you sufficient time, without rushing you through your consultation? (Tick all that apply)



Resps (4670)



Q23: Which professional(s) is best at giving you sufficient time, without rushing you through your consultation? (Tick all that apply)

Gender	a. Specialist/gastroenterologist service	b. Family/general physician clinic/service	c. Nurse	d. Counsellor or psychologist	e. Other	f. Don't know/Not applicable	Resps
Male	69.5	31.8	17.9	3.9	2.9	10.8	1549
Female	62.9	36.6	20.8	5.3	4.2	10.6	3093
Not Stated	28.6	21.4	7.1	0.0	3.6	10.7	28

Age Group	a.	b.	c.	d.	e.	f.	Resps
<18 yrs	77.3	36.2	22.1	11.0	3.7	8.0	163
19-34	61.8	33.0	21.8	5.6	3.6	11.6	2000
35-54	66.1	36.8	19.0	4.2	4.4	10.3	2020
55+	70.0	36.0	14.6	1.9	1.9	9.2	467



Q23: Which professional(s) is best at giving you sufficient time, without rushing you through your consultation? (Tick all that apply)

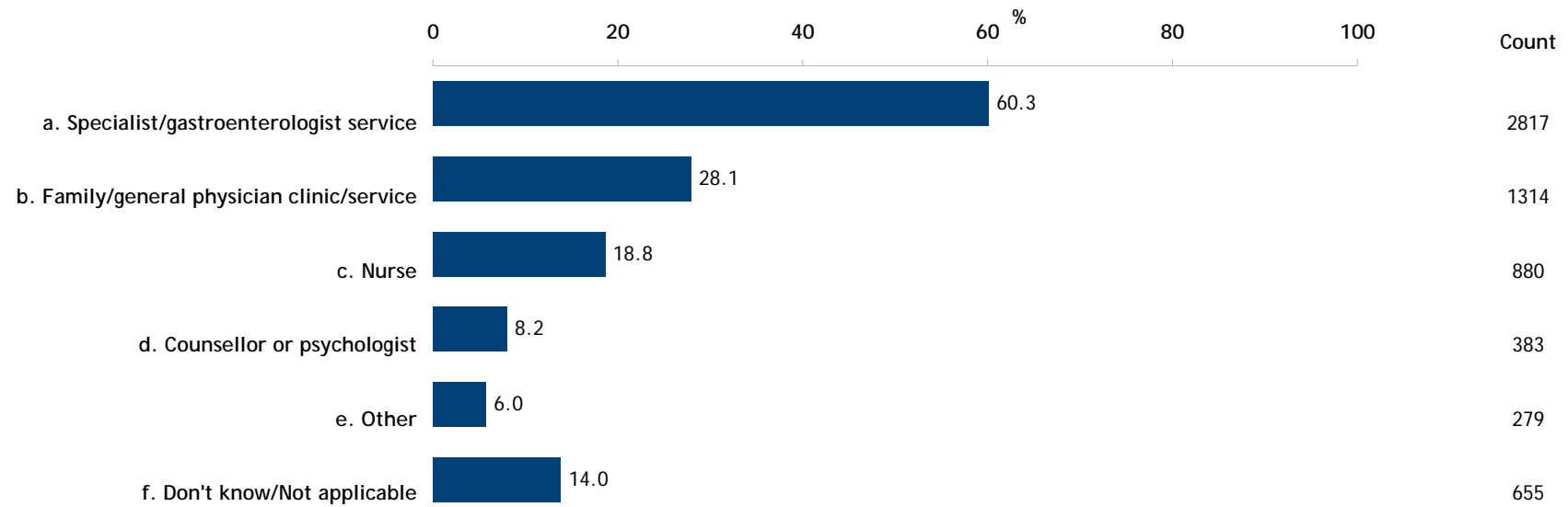
Employment and Disability Status	a. Specialist/gastroenterologist service	b. Family/general physician clinic/service	c. Nurse	d. Counsellor or psychologist	e. Other	f. Don't know/Not applicable	Resps
Fully employed	66.8	31.8	19.2	3.0	3.4	10.1	2223
Under-employed due to IBD	53.6	44.0	20.0	7.0	6.1	10.9	459
Un-employed due to IBD	56.6	39.3	22.5	7.0	5.2	12.7	387
Student	66.4	33.3	23.3	7.6	3.6	11.4	673
Retired	72.1	33.3	15.5	4.3	3.1	7.8	258
Disabled	68.0	42.5	18.1	8.6	6.5	8.1	651
Seeking disability	64.7	37.0	15.2	7.6	4.3	9.2	184
Unable to receive disability status	52.8	40.1	19.1	5.6	4.9	12.3	324
Other	65.5	37.5	19.3	5.9	5.6	11.3	461
N/A	67.7	31.3	12.8	3.1	5.6	14.9	195

Type of IBD	a.	b.	c.	d.	e.	f.	Resps
Ulcerative colitis	62.5	30.5	21.0	3.9	3.1	12.0	1535
Crohn's Disease	67.5	37.4	19.5	5.2	4.0	9.8	2914
Indeterminate Colitis	50.9	34.3	26.9	4.6	3.7	12.0	108
Microscopic/collagenous colitis	38.9	38.9	0.0	16.7	16.7	16.7	18
Not yet confirmed	47.1	25.5	11.8	2.0	7.8	19.6	51
Other	38.9	50.0	0.0	11.1	11.1	5.6	18



Q24:

Which professional(s) do you feel best understands the full picture of how IBD impacts your life - not just the medical problem? (Tick all that apply)



Resps (4670)



Q24: Which professional(s) do you feel best understands the full picture of how IBD impacts your life - not just the medical problem? (Tick all that apply)

Gender	a. Specialist/gastroenterologist service	b. Family/general physician clinic/service	c. Nurse	d. Counsellor or psychologist	e. Other	f. Don't know/Not applicable	Resps
Male	65.1	27.4	17.0	7.4	5.2	13.0	1549
Female	58.2	28.7	19.9	8.6	6.4	14.5	3093
Not Stated	28.6	10.7	7.1	3.6	3.6	10.7	28

Age Group	a.	b.	c.	d.	e.	f.	Resps
<18 yrs	69.3	23.3	22.1	14.1	8.0	10.4	163
19-34	58.0	24.6	20.5	9.8	6.5	15.0	2000
35-54	61.7	31.4	18.2	7.2	5.6	13.6	2020
55+	63.0	31.7	14.1	3.9	4.7	13.5	467



Q24: Which professional(s) do you feel best understands the full picture of how IBD impacts your life - not just the medical problem? (Tick all that apply)

Employment and Disability Status	a. Specialist/gastroenterologist service	b. Family/general physician clinic/service	c. Nurse	d. Counsellor or psychologist	e. Other	f. Don't know/Not applicable	Resps
Fully employed	63.5	25.7	18.8	6.0	5.6	12.8	2223
Under-employed due to IBD	52.7	34.0	21.1	12.4	7.8	14.6	459
Un-employed due to IBD	50.1	32.6	23.5	12.7	7.5	15.2	387
Student	60.0	22.6	21.0	11.4	5.6	15.3	673
Retired	68.6	34.1	16.3	7.0	5.4	10.1	258
Disabled	64.2	38.1	17.4	14.1	7.4	10.6	651
Seeking disability	54.3	25.5	16.3	9.8	6.5	16.3	184
Unable to receive disability status	50.3	34.9	21.3	9.3	6.5	14.8	324
Other	59.0	26.5	16.9	11.3	8.7	15.4	461
N/A	60.5	25.1	8.2	5.6	6.7	22.6	195

Type of IBD	a.	b.	c.	d.	e.	f.	Resps
Ulcerative colitis	59.9	23.2	20.0	7.2	5.5	14.2	1535
Crohn's Disease	61.9	30.9	18.6	8.7	6.2	13.5	2914
Indeterminate Colitis	50.9	24.1	23.1	10.2	5.6	15.7	108
Microscopic/collagenous colitis	27.8	33.3	5.6	16.7	16.7	33.3	18
Not yet confirmed	37.3	27.5	11.8	5.9	5.9	31.4	51
Other	27.8	38.9	0.0	11.1	16.7	22.2	18

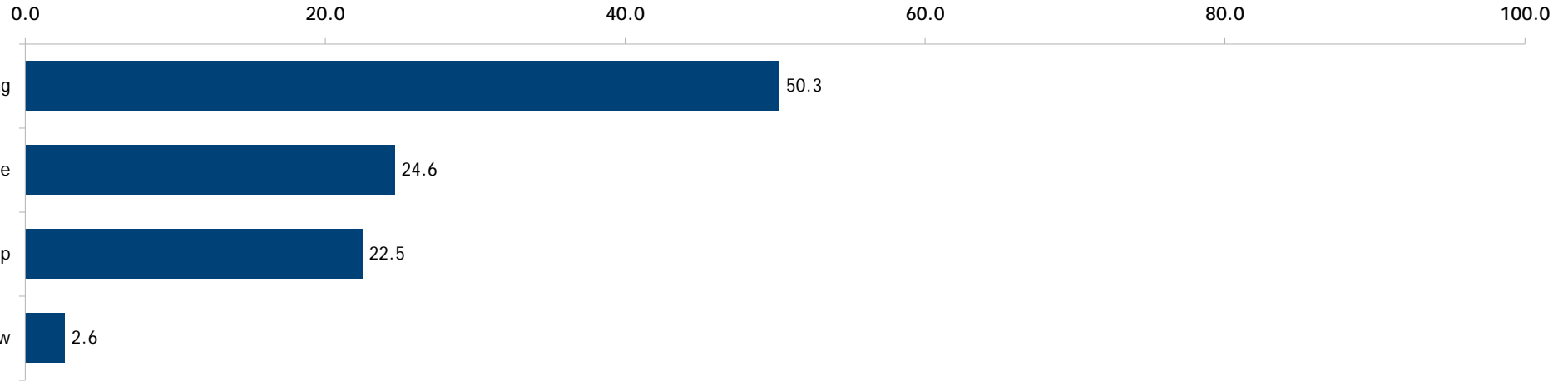


Section C : The IMPACT that IBD has on YOUR Life



Q25: What is the current state of your IBD disease?

Overall



	% In remission/not flaring	% Chronically active	% Active periodic flare-up	% Not applicable/don't know	Resps
EFCCA Overall	50	25	22	3	4651

Gender

	% In remission/not flaring	% Chronically active	% Active periodic flare-up	% Not applicable/don't know	Resps
Male	53	23	22	2	1548
Female	49	25	23	3	3088
Not Stated	27	33	27	13	15



Q25: What is the current state of your IBD disease?

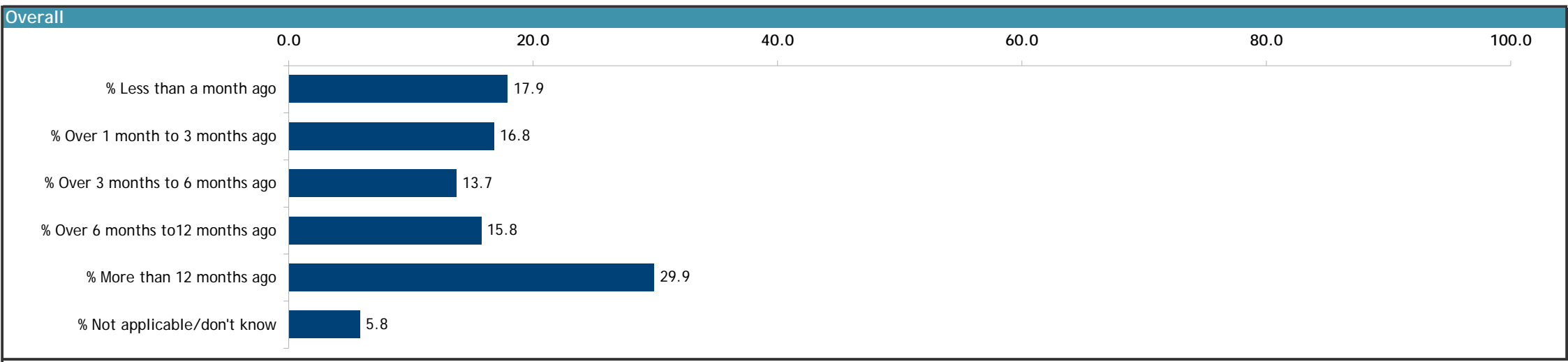
Age Group	% In remission/not flaring	% Chronically active	% Active periodic flare-up	% Not applicable/don't know	Resps
<18 yrs	47	27	23	4	163
19-34	50	24	23	3	1997
35-54	52	25	21	2	2019
55+	46	26	25	3	465

Employment and Disability Status	% In remission/not flaring	% Chronically active	% Active periodic flare-up	% Not applicable/don't know	Resps
Fully employed	55	20	23	3	2221
Under-employed due to IBD	42	32	22	3	458
Un-employed due to IBD	36	37	25	2	387
Student	49	27	21	2	672
Retired	44	30	24	2	258
Disabled	45	36	17	2	651
Seeking disability	41	36	20	3	184
Unable to receive disability status	39	28	30	3	323
Other	55	22	19	4	461
N/A	54	22	20	4	194

Type of IBD	% In remission/not flaring	% Chronically active	% Active periodic flare-up	% Not applicable/don't know	Resps
Ulcerative colitis	50	20	26	3	1533
Crohn's Disease	51	26	20	2	2910
Indeterminate Colitis	47	26	25	2	108
Microscopic/collagenous colitis	22	44	33	0	18
Not yet confirmed	18	34	40	8	50
Other	33	44	22	0	18



Q26: When was your last flare (before this one if you are currently experiencing one)?



	% Less than a month ago	% Over 1 month to 3 months ago	% Over 3 months to 6 months ago	% Over 6 months to 12 months ago	% More than 12 months ago	% Not applicable/don't know	Resps
EFCCA Overall	18	17	14	16	30	6	4602

Gender	% Less than a month ago	% Over 1 month to 3 months ago	% Over 3 months to 6 months ago	% Over 6 months to 12 months ago	% More than 12 months ago	% Not applicable/don't know	Resps
Male	18	18	13	16	30	5	1527
Female	18	16	14	16	30	6	3060
Not Stated	20	27	7	7	27	13	15



Q26: When was your last flare (before this one if you are currently experiencing one)?

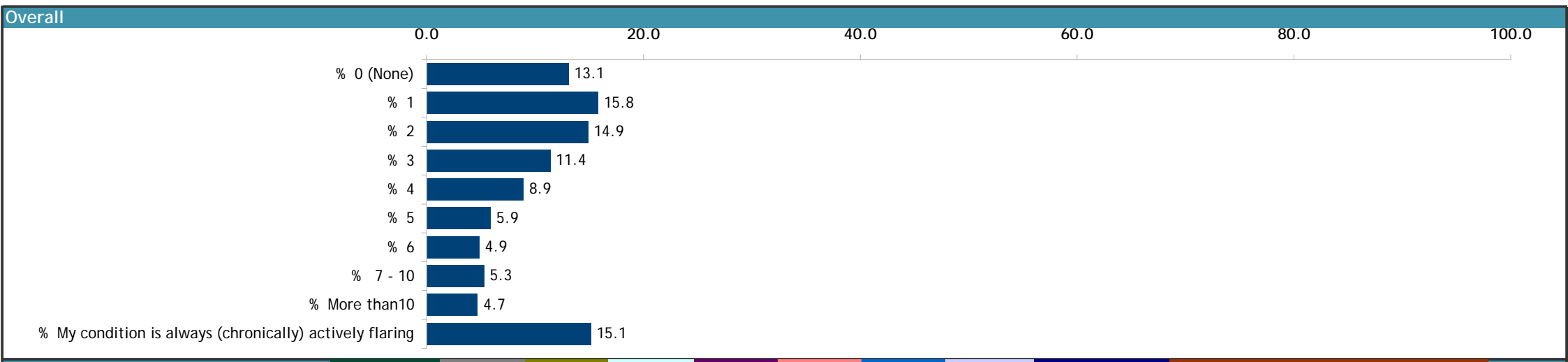
Age Group	% Less than a month ago	% Over 1 month to 3 months ago	% Over 3 months to 6 months ago	% Over 6 months to 12 months ago	% More than 12 months ago	% Not applicable/don't know	Resps
<18 yrs	21	20	18	19	18	4	162
19-34	19	18	15	17	26	5	1996
35-54	17	16	12	15	34	6	1987
55+	19	14	14	13	33	7	449

Employment and Disability Status	% Less than a month ago	% Over 1 month to 3 months ago	% Over 3 months to 6 months ago	% Over 6 months to 12 months ago	% More than 12 months ago	% Not applicable/don't know	Resps
Fully employed	15	17	14	16	33	5	2196
Under-employed due to IBD	18	21	13	16	27	5	457
Un-employed due to IBD	28	19	13	15	19	7	383
Student	20	18	15	17	24	5	670
Retired	20	10	13	14	33	10	252
Disabled	19	15	12	15	32	8	640
Seeking disability	22	16	14	16	23	8	182
Unable to receive disability status	22	24	15	13	19	7	317
Other	19	16	12	15	33	5	457
N/A	17	16	13	14	35	6	191

Type of IBD	% Less than a month ago	% Over 1 month to 3 months ago	% Over 3 months to 6 months ago	% Over 6 months to 12 months ago	% More than 12 months ago	% Not applicable/don't know	Resps
Ulcerative colitis	17	20	15	16	28	5	1518
Crohn's Disease	18	15	13	15	32	7	2880
Indeterminate Colitis	25	19	16	17	21	3	106
Microscopic/collagenous colitis	29	29	18	12	0	12	17
Not yet confirmed	40	18	14	10	10	8	50
Other	44	6	17	11	11	11	18



Q27: How many flare-ups would you say you have experienced in the last two years?



	% 0 (None)	% 1	% 2	% 3	% 4	% 5	% 6	% 7 - 10	% More than 10	% My condition is always (chronically) actively flaring	Resps
EFCCA Overall	13	16	15	11	9	6	5	5	5	15	4624

Gender	% 0 (None)	% 1	% 2	% 3	% 4	% 5	% 6	% 7 - 10	% More than 10	% My condition is always (chronically) actively flaring	Resps
Male	14	17	15	12	8	6	5	6	5	12	1539
Female	13	15	15	11	9	6	5	5	5	17	3070
Not Stated	20	27	7	7	7	0	13			20	15



Q27: How many flare-ups would you say you have experienced in the last two years?

Age Group	% 0 (None)	% 1	% 2	% 3	% 4	% 5	% 6	% 7 - 10	% More than 10	% My condition is always (chronically) actively flaring			Resps
<18 yrs	12	17	15	15	8	6	4	4	4	15			163
19-34	10	16	16	12	10	6	5	5	5	15			1988
35-54	15	17	14	11	8	6	5	5	5	15			2009
55+	16	12	16	12	8	4	5	5	5	16			456

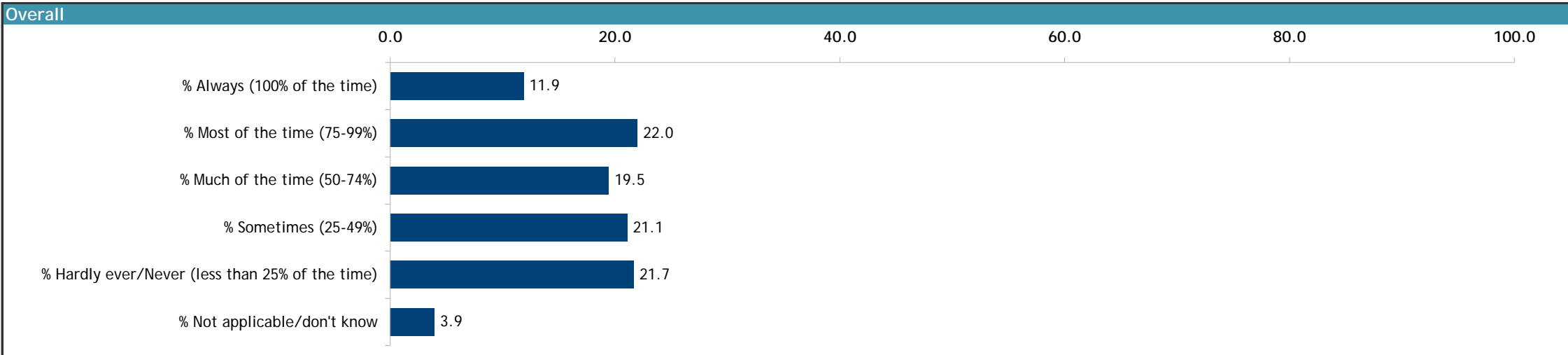
Employment and Disability Status													Resps
Fully employed	15	17	16	12	10	6	5	5	4	10			2209
Under-employed due to IBD	8	13	12	13	8	9	5	6	6	21			457
Un-employed due to IBD	5	11	14	9	10	5	4	7	7	28			385
Student	10	19	15	12	10	5	5	6	5	14			668
Retired	19	13	14	10	7	4	3	4	4	23			252
Disabled	13	12	12	10	7	6	4	7	4	24			641
Seeking disability	7	12	15	14	5	4	4	6	7	26			183
Unable to receive disability status	7	5	12	14	11	6	7	6	8	23			323
Other	15	16	17	11	9	5	4	5	4	15			457
N/A	16	16	15	14	8	6	4	5	3	12			194

Type of IBD													Resps
Ulcerative colitis	10	17	16	13	10	6	6	6	4	12			1520
Crohn's Disease	15	16	14	11	8	6	4	5	5	16			2896
Indeterminate Colitis	7	8	16	18	7	6	3	6	6	21			108
Microscopic/collagenous colitis	6	22	6	11	11	6	11			28			18
Not yet confirmed	2	10	16	4	8	4	10	4	6	36			50
Other	6	6	6	11	11	11	0	11		39			18



The effect on you of an active flare/ chronically active flare

Q28: During your current or most recent flare, how often do/did you have to cancel or reschedule an engagement, meeting, etc. because of your IBD? (select the option that most closely represents your own experience)



	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
EFCCA Overall	12	22	19	21	22	4	4637
Gender							Resps
Male	11	21	18	21	25	5	1542
Female	12	23	20	21	20	4	3083
Not Stated	25		42		17	17	12



The effect on you of an active flare/ chronically active flare

Q28: During your current or most recent flare, how often do/did you have to cancel or reschedule an engagement, meeting, etc. because of your IBD? (select the option that most closely represents your own experience)

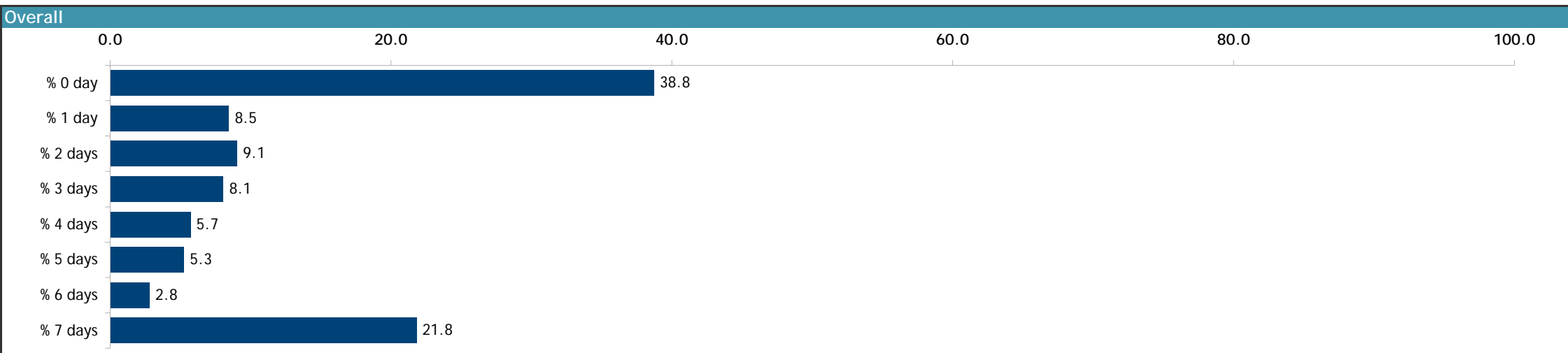
Age Group	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
<18 yrs	14	22	13	20	19	12	162
19-34	11	26	21	20	19	3	1996
35-54	13	19	18	23	23	4	2009
55+	10	16	20	20	29	5	466

Employment and Disability Status	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
Fully employed	10	19	17	23	28	3	2214
Under-employed due to IBD	13	26	27	21	10	2	457
Un-employed due to IBD	25	33	23	13	6	2	386
Student	12	23	20	21	20	4	672
Retired	10	17	18	18	32	5	257
Disabled	15	27	21	18	15	3	648
Seeking disability	25	28	27	13	4	2	184
Unable to receive disability status	15	33	24	17	9	2	322
Other	10	23	17	21	24	6	460
N/A	6	15	19	27	24	9	195

Type of IBD	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
Ulcerative colitis	11	20	19	21	25	3	1529
Crohn's Disease	12	23	19	21	20	4	2900
Indeterminate Colitis	12	26	24	16	20	2	108
Microscopic/collagenous colitis	17	28	11	28	11	6	18
Not yet confirmed	20	14	26	20	10	10	50
Other	28	28	17	11	17	0	18



Q29: During your current or most recent flare, how many days in a week do/did you experience bleeding from your gastrointestinal tract? (select the option that most closely represents your own experience)



	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
EFCCA Overall	39	8	9	8.1	6	5	3	22	4361

Gender	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Male	38	8	9	7.9	6	6	4	21	1453
Female	39	9	9	8.1	5	5	2	22	2894
Not Stated	36	7	7	14.3	14	7	0	14	14



Q29: During your current or most recent flare, how many days in a week do/did you experience bleeding from your gastrointestinal tract? (select the option that most closely represents your own experience)

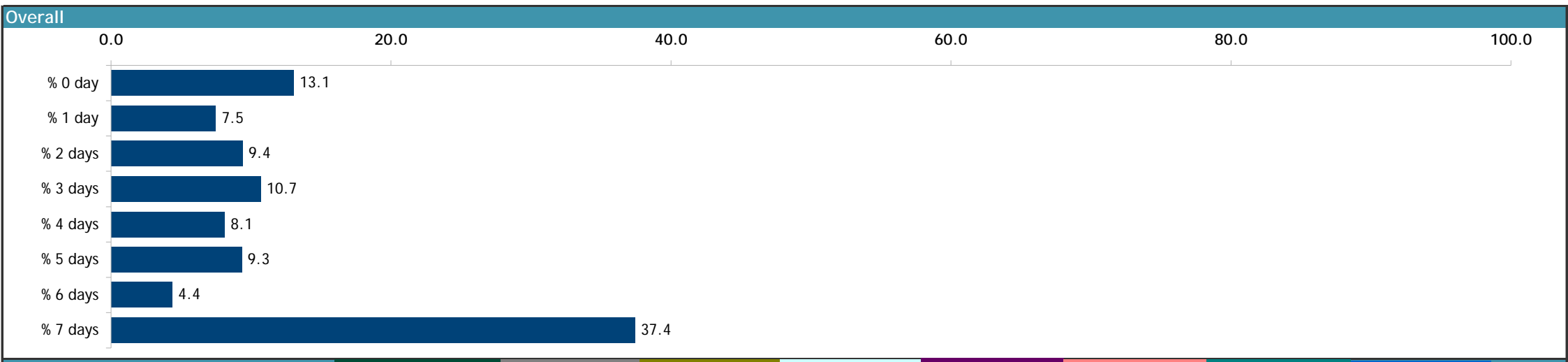
Age Group	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
<18 yrs	42	10	7	8	4	8	3	18	142
19-34	34	8	9	9	7	6	3	23	1893
35-54	41	9	9	8	5	4	2	22	1890
55+	46	6	11	8	6	3	3	18	430

Employment and Disability Status	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Fully employed	38	8	9	9	5	5	3	23	2116
Under-employed due to IBD	37	9	11	8	6	7	2	19	424
Un-employed due to IBD	38	10	10	7	6	5	2	22	365
Student	34	9	8	8	6	7	3	24	622
Retired	53	6	10	5	6	2	3	14	244
Disabled	45	10	10	8	5	6	3	14	610
Seeking disability	34	7	7	14	5	6	2	25	170
Unable to receive disability status	43	5	9	7	7	3	3	22	297
Other	41	9	7	7	6	7	2	21	424
N/A	41	9	7	7	8	4	3	21	180

Type of IBD	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Ulcerative colitis	12	5	7	9	7	9	5	46	1385
Crohn's Disease	52	10	10	7	5	4	2	10	2781
Indeterminate Colitis	26	8	9	10	6	7	2	32	98
Microscopic/collagenous colitis	50	28	17	6	0	0	0	0	18
Not yet confirmed	50	10	6	10	2	4	2	15	48
Other	50	6	22	0	6	6	0	11	18



Q30: During your current or most recent flare, how many days in a week do/did you experience cramping pain in your abdomen? (select the option that most closely represents your own experience)



	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
EFCCA Overall	13	7	9	10.7	8	9	4	37	4216

Gender	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Male	17	8	11	11.1	9	9	4	31	1441
Female	11	7	8	10.5	8	10	5	41	2762
Not Stated	15	8	0	7.7	8	0	15	46	13



Q30: During your current or most recent flare, how many days in a week do/did you experience cramping pain in your abdomen? (select the option that most closely represents your own experience)

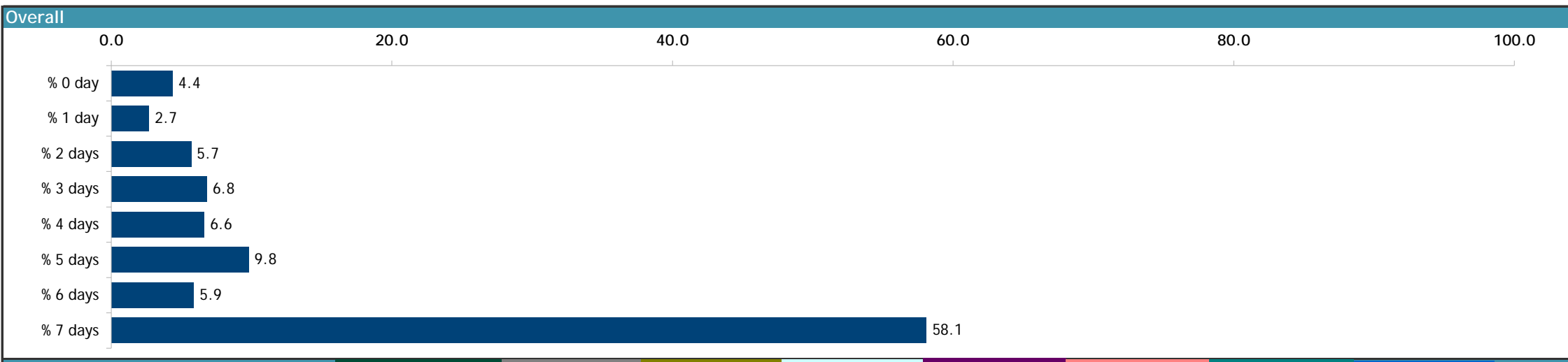
Age Group	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
<18 yrs	17	5	9	14	5	10	6	34	139
19-34	10	5	9	11	8	10	5	42	1822
35-54	13	9	9	10	8	9	4	36	1824
55+	24	11	13	11	7	9	3	22	425

Employment and Disability Status	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Fully employed	15	9	9	10	8	9	5	35	2080
Under-employed due to IBD	6	7	10	10	7	11	4	45	403
Un-employed due to IBD	6	3	5	11	10	13	4	48	341
Student	13	5	8	12	9	9	4	39	603
Retired	25	11	14	12	5	8	5	20	237
Disabled	12	5	10	10	8	11	5	39	567
Seeking disability	11	4	6	8	12	13	6	42	160
Unable to receive disability status	7	4	8	10	9	10	3	50	289
Other	14	9	10	9	8	9	3	38	416
N/A	12	8	16	13	7	8	5	30	171

Type of IBD	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Ulcerative colitis	17	7	8	11	7	10	4	36	1410
Crohn's Disease	11	8	10	11	9	9	5	38	2618
Indeterminate Colitis	7	7	8	16	8	8	1	44	96
Microscopic/collagenous colitis	13	6	19	6	19	0	0	38	16
Not yet confirmed	6	4	4	13	11	6	0	55	47
Other	6	13	6	0	13	19	6	38	16



Q31: During your current or most recent flare, how many days in a week do/did you feel tired, weak or worn out? (select the option that most closely represents your own experience)



	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
EFCCA Overall	4	3	6	6.8	7	10	6	58	3996

Gender	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Male	6	3	7	7.8	8	11	7	51	1380
Female	3	3	5	6.3	6	9	5	62	2604
Not Stated	8	0	0	8.3	0	0	0	83	12



Q31: During your current or most recent flare, how many days in a week do/did you feel tired, weak or worn out? (select the option that most closely represents your own experience)

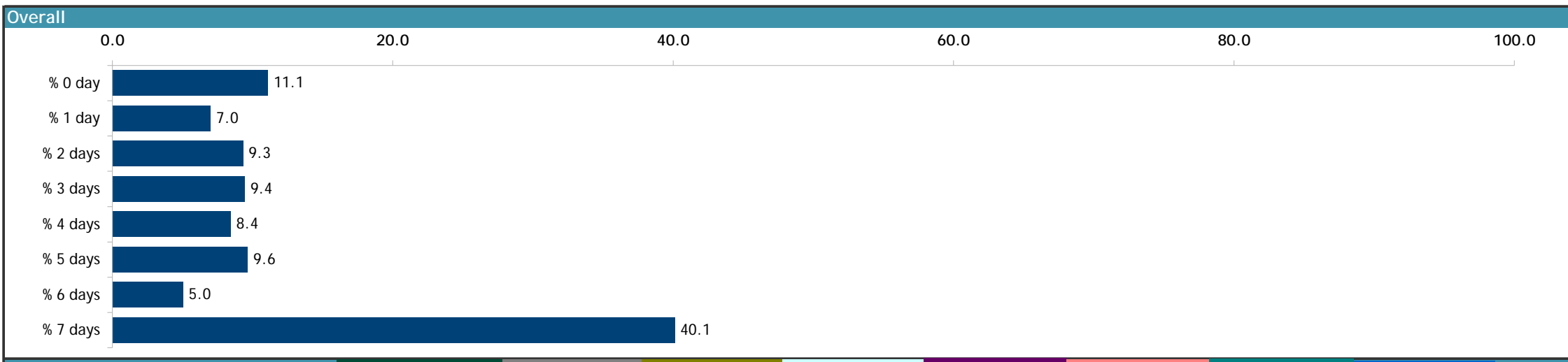
Age Group	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
<18 yrs	8	4	5	9	5	11	7	51	137
19-34	3	2	4	6	7	10	8	60	1737
35-54	4	3	6	6	6	10	4	59	1712
55+	8	4	9	12	7	7	4	48	404

Employment and Disability Status	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Fully employed	5	3	7	7	7	11	6	55	1990
Under-employed due to IBD	2	1	4	6	5	9	6	67	377
Un-employed due to IBD	1	1	2	3	6	6	6	76	322
Student	4	3	6	7	7	10	6	55	586
Retired	8	4	13	15	6	6	5	43	218
Disabled	2	2	4	6	6	10	8	63	530
Seeking disability	1	1	2	5	6	12	8	64	154
Unable to receive disability status	1	0	3	5	8	9	4	70	270
Other	5	4	6	8	8	9	6	55	387
N/A	7	3	7	8	7	10	5	53	166

Type of IBD	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Ulcerative colitis	6	3	5	6	6	10	6	58	1349
Crohn's Disease	4	2	6	7	7	9	6	58	2465
Indeterminate Colitis	4	4	8	13	2	9	2	58	93
Microscopic/collagenous colitis	0	7	0	13	7	20	7	47	15
Not yet confirmed	2	2	4	9	7	16	2	58	45
Other	0	13	0	7	7	20	7	53	15



Q32: During your current or most recent flare, how many days in a week do/did you feel a sudden, uncontrollable urge for a bowel movement? (select the option that most closely represents your own experience)



	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
EFCCA Overall	11	7	9	9.4	8	10	5	40	4210

Gender	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Male	13	8	9	10.0	8	9	5	38	1433
Female	10	6	9	9.1	8	10	5	41	2765
Not Stated	8	0	8	8.3	8	8	0	58	12



Q32: During your current or most recent flare, how many days in a week do/did you feel a sudden, uncontrollable urge for a bowel movement? (select the option that most closely represents your own experience)

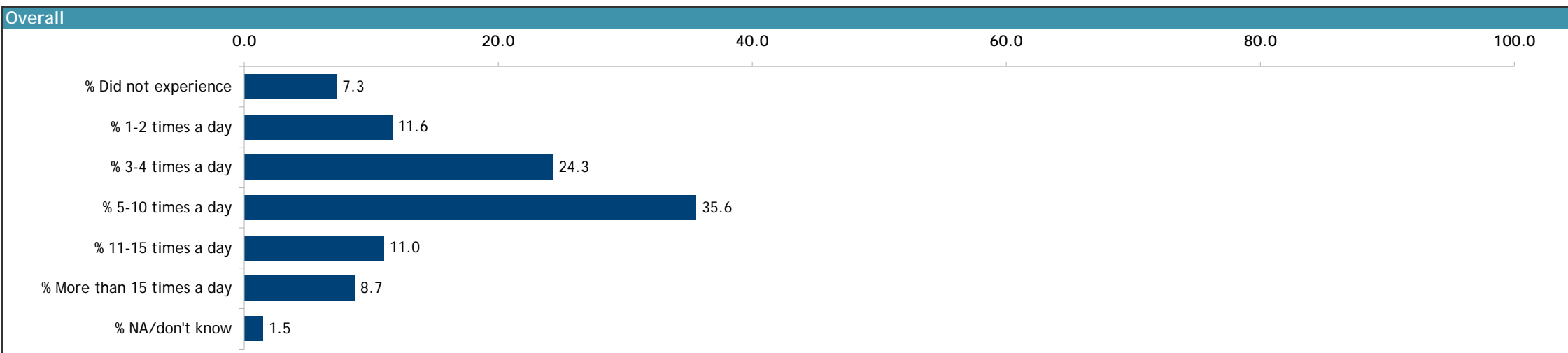
Age Group	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
<18 yrs	22	9	8	9	8	9	4	31	147
19-34	10	7	9	9	9	10	6	40	1830
35-54	11	7	9	10	8	10	4	41	1807
55+	12	9	11	8	7	10	6	39	420

Employment and Disability Status	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Fully employed	11	8	9	11	8	9	5	39	2057
Under-employed due to IBD	9	5	11	8	9	12	6	42	407
Un-employed due to IBD	7	4	8	5	8	11	5	52	351
Student	16	7	9	9	8	10	6	35	612
Retired	14	10	9	8	8	10	5	37	229
Disabled	11	3	7	8	7	10	6	47	564
Seeking disability	6	5	5	6	9	10	6	54	162
Unable to receive disability status	5	5	7	6	11	13	5	48	295
Other	14	6	10	9	8	10	5	38	413
N/A	6	7	10	12	7	11	7	39	177

Type of IBD	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Ulcerative colitis	6	6	7	9	7	10	4	50	1388
Crohn's Disease	14	7	11	10	9	10	5	35	2633
Indeterminate Colitis	4	9	3	8	14	8	6	46	97
Microscopic/collagenous colitis	7	7	0	21	21	0	0	43	14
Not yet confirmed	10	6	13	8	13	8	6	35	48
Other	19	19	6	6	13	13	0	25	16



Q33: During your current or most recent flare, how many runny stools or episodes of diarrhoea do/did you experience in the course of a typical day?
 (select the option that most closely represents your own experience)



	% Did not experience	% 1-2 times a day	% 3-4 times a day	% 5-10 times a day	% 11-15 times a day	% More than 15 times a day	% NA/don't know	Resps
EFCCA Overall	7	12	24	36	11	9	1	4638

Gender	% Did not experience	% 1-2 times a day	% 3-4 times a day	% 5-10 times a day	% 11-15 times a day	% More than 15 times a day	% NA/don't know	Resps
Male	8	15	25	33	11	6	1	1543
Female	7	10	24	37	11	10	1	3082
Not Stated		23		54	8	0	15	13



Q33: During your current or most recent flare, how many runny stools or episodes of diarrhoea do/did you experience in the course of a typical day? (select the option that most closely represents your own experience)

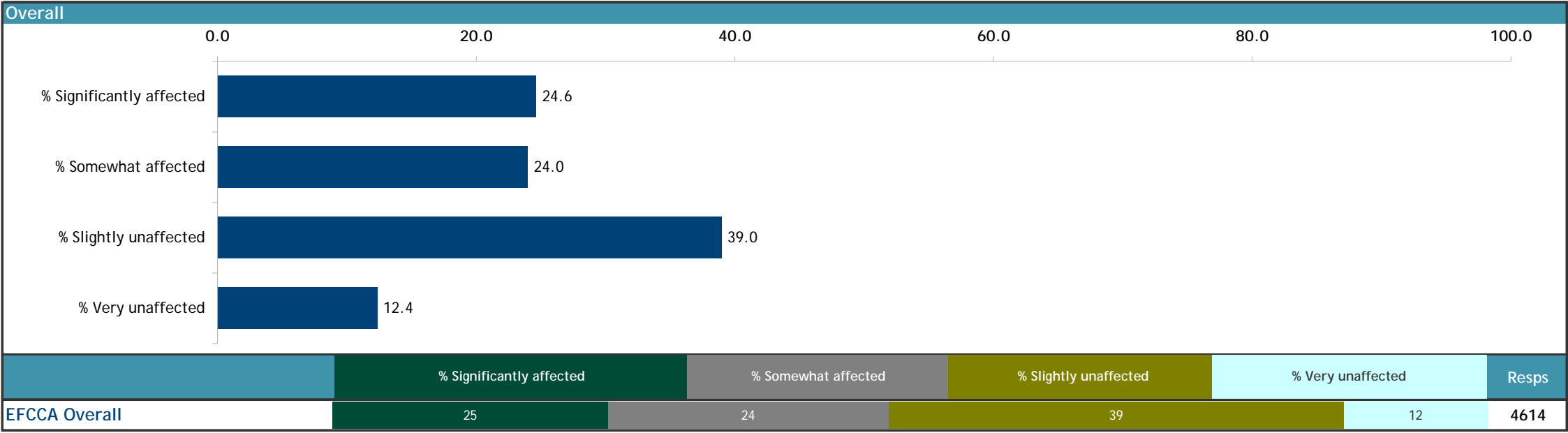
Age Group	% Did not experience	% 1-2 times a day	% 3-4 times a day	% 5-10 times a day	% 11-15 times a day	% More than 15 times a day	% NA/don't know	Resps
<18 yrs	15	18	24	29	7	4	2	161
19-34	7	12	25	36	11	8	1	1998
35-54	7	11	23	36	12	10	2	2009
55+	7	11	26	35	11	8	2	464

Employment and Disability Status	% Did not experience	% 1-2 times a day	% 3-4 times a day	% 5-10 times a day	% 11-15 times a day	% More than 15 times a day	% NA/don't know	Resps
Fully employed	8	13	26	35	10	7	1	2214
Under-employed due to IBD	5	8	20	40	13	11	2	459
Un-employed due to IBD	3	8	19	39	13	17	1	387
Student	11	14	23	34	10	6	1	671
Retired	5	13	28	29	11	11	4	256
Disabled	5	7	18	37	15	15	3	646
Seeking disability	2	8	19	39	16	14	2	184
Unable to receive disability status	3	9	21	46	11	10	1	323
Other	10	9	26	35	11	7	3	459
N/A	6	15	31	31	10	6	2	193

Type of IBD	% Did not experience	% 1-2 times a day	% 3-4 times a day	% 5-10 times a day	% 11-15 times a day	% More than 15 times a day	% NA/don't know	Resps
Ulcerative colitis	6	12	22	36	14	11	1	1532
Crohn's Disease	8	12	26	35	10	8	2	2898
Indeterminate Colitis	6	13	15	38	10	15	3	108
Microscopic/collagenous colitis	6	6	22	28	33	6	0	18
Not yet confirmed	4	12	34	34	10	4	2	50
Other	17	11	22	39	6	6	0	18



Q34: In between flares, my life is still significantly negatively impacted by symptoms of IBD compared to people without IBD.



Gender	% Significantly affected	% Somewhat affected	% Slightly unaffected	% Very unaffected	Resps
Male	24	25	37	14	1531
Female	25	24	40	12	3068
Not Stated	33	27	20	20	15



Q34: In between flares, my life is still significantly negatively impacted by symptoms of IBD compared to people without IBD.

Age Group	% Significantly affected	% Somewhat affected	% Slightly unaffected	% Very unaffected	Resps
<18 yrs	21	27	35	18	159
19-34	24	23	41	11	1984
35-54	25	25	38	12	2004
55+	28	22	33	17	460

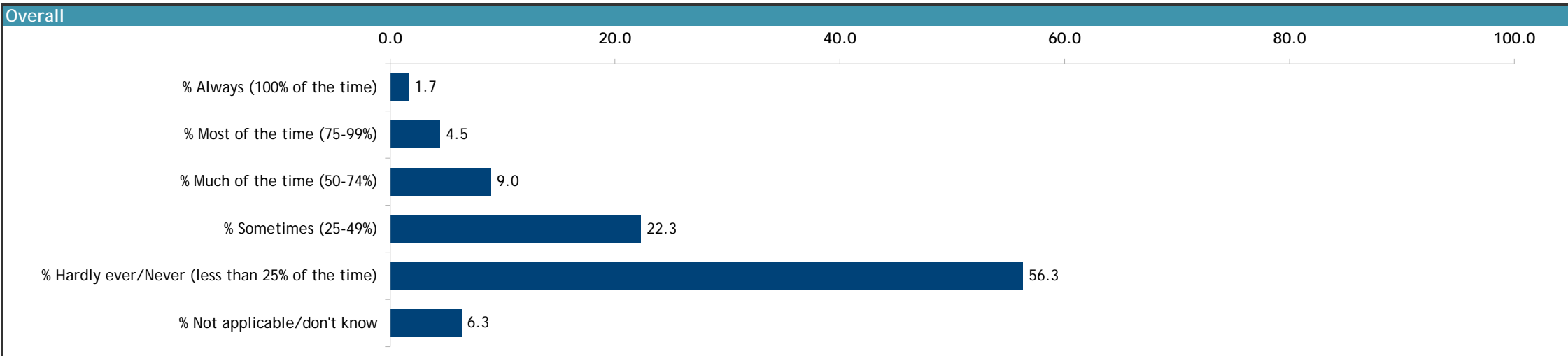
Employment and Disability Status	% Significantly affected	% Somewhat affected	% Slightly unaffected	% Very unaffected	Resps
Fully employed	19	21	46	14	2204
Under-employed due to IBD	31	34	31	3	458
Un-employed due to IBD	45	32	20	3	383
Student	23	22	39	16	666
Retired	28	24	33	16	255
Disabled	35	30	28	6	643
Seeking disability	48	30	17	5	183
Unable to receive disability status	36	35	24	4	322
Other	22	22	40	16	455
N/A	14	28	37	21	191

Type of IBD	% Significantly affected	% Somewhat affected	% Slightly unaffected	% Very unaffected	Resps
Ulcerative colitis	24	23	39	14	1518
Crohn's Disease	25	24	39	12	2888
Indeterminate Colitis	28	26	35	11	108
Microscopic/collagenous colitis	33	33	28	6	18
Not yet confirmed	30	32	30	8	50
Other	39	28	6	28	18



Non-flare

Q35: During your current or most recent period NOT experiencing a flare, how often do/did you have to cancel or reschedule an engagement, meeting, etc. because of your bowel disease?



	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
EFCCA Overall	2	4	9	22	56	6	4582

Gender	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
Male	2	4	8	21	58	7	1519
Female	2	4	9	23	56	6	3052
Not Stated			9	36	45	9	11



Non-flare

Q35: During your current or most recent period NOT experiencing a flare, how often do/did you have to cancel or reschedule an engagement, meeting, etc. because of your bowel disease?

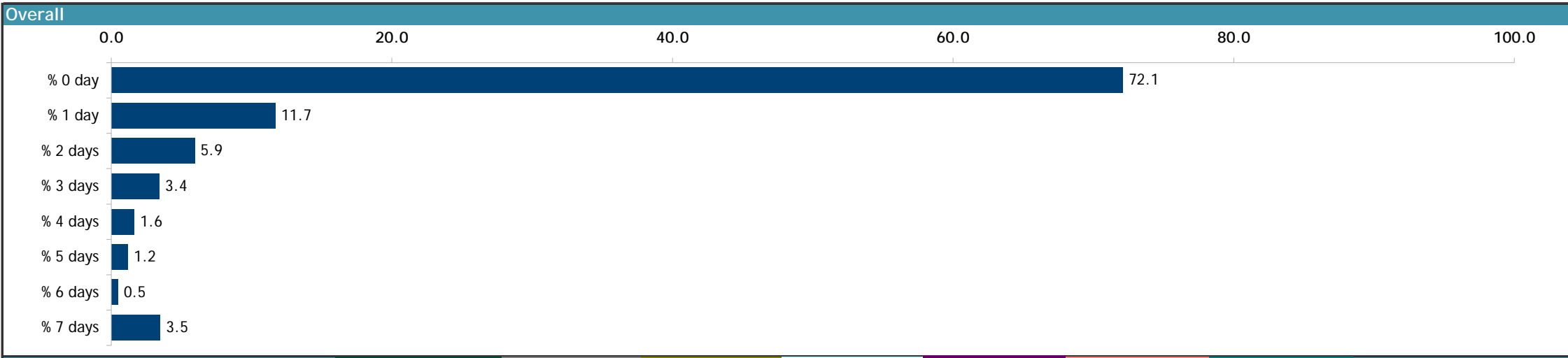
Age Group	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	Not applicable/don't know	Resps
<18 yrs	4	6	9	19	52	10	161
19-34	2	4	8	22	59	5	1979
35-54	2	5	9	23	55	6	1986
55+	2	6	10	22	51	9	452

Employment and Disability Status	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	Not applicable/don't know	Resps
Fully employed	2	6	18	66	6	2193	
Under-employed due to IBD	2	5	12	31	47	2	452
Un-employed due to IBD	4	11	20	34	28	3	380
Student	2	4	8	18	61	7	667
Retired	1	6	15	21	48	8	251
Disabled	3	7	15	30	39	6	644
Seeking disability	3	13	14	31	35	4	179
Unable to receive disability status	3	8	19	33	34	3	320
Other	2	4	7	23	58	7	454
N/A	3	8	21	54	14	186	

Type of IBD	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	Not applicable/don't know	Resps
Ulcerative colitis	2	4	7	20	61	6	1499
Crohn's Disease	2	4	10	23	55	6	2877
Indeterminate Colitis	3	7	10	23	51	6	108
Microscopic/collagenous colitis		11	11	22	33	22	18
Not yet confirmed	2	6	10	19	48	15	48
Other	6	11	6	17	61	0	18



Q36: During your current or most recent period NOT experiencing a flare, how many days in a week do/did you experience bleeding from your gastrointestinal tract? (select the option that most closely represents your own experience)



	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
EFCCA Overall	72		6	3.4	2	10	3		4524

Gender	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Male	70		7	3.4	2	11	4		1495
Female	73		6	3.4	1	10	3		3019
Not Stated	55			9.1	18				11



Q36: During your current or most recent period NOT experiencing a flare, how many days in a week do/did you experience bleeding from your gastrointestinal tract? (select the option that most closely represents your own experience)

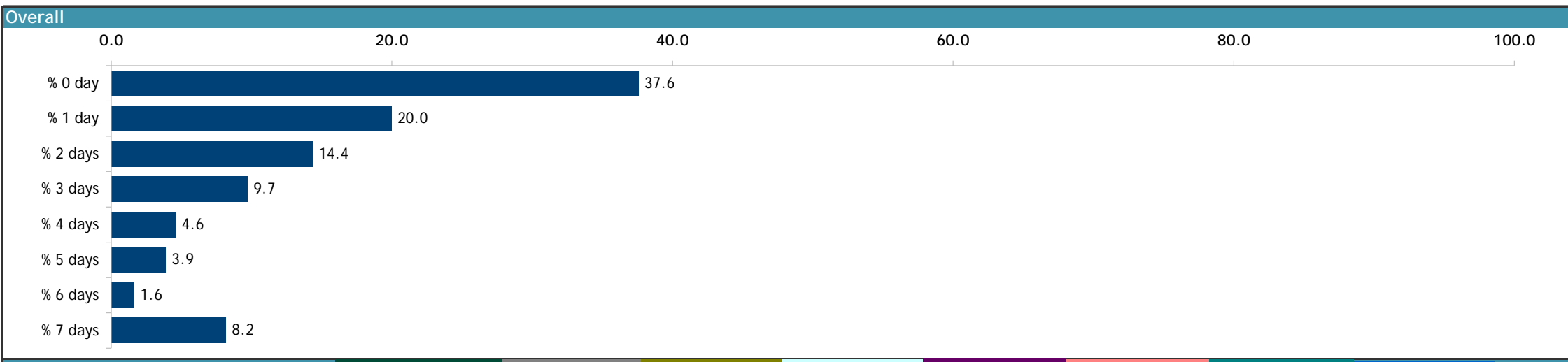
Age Group	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
<18 yrs	70	12	6	5	1	1	1	3	155
19-34	72	14	6	3	2	1	0	3	1952
35-54	73	10	5	4	2	1	0	4	1965
55+	70	9	8	4	1	1	1	4	448

Employment and Disability Status	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Fully employed	74	12	5	3	1	1	0	3	2175
Under-employed due to IBD	71	13	6	2	2	2	0	4	450
Un-employed due to IBD	62	12	7	6	2	2	1	7	372
Student	72	14	5	3	1	1	0	2	654
Retired	75	9	8	2	2	1	1	2	244
Disabled	70	11	7	4	2	2	1	3	626
Seeking disability	65	14	3	5	2	5	1	6	176
Unable to receive disability status	68	12	9	3	2	3	1	2	311
Other	77	8	4	4	2	1	0	4	448
N/A	68	12	9	6	1	0	1	4	186

Type of IBD	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Ulcerative colitis	66	12	7	4	2	2	1	6	1486
Crohn's Disease	75	11	5	3	1	1	0	2	2833
Indeterminate Colitis	62	13	7	6	3	3	1	6	107
Microscopic/collagenous colitis	83	17	0	0	0	0	0	0	18
Not yet confirmed	84	10	2	0	2	0	2	0	49
Other	78	6	11	0	0	0	6	0	18



Q37: During your current or most recent period NOT experiencing a flare, how many days in a week do/did you experience cramping pain in your abdomen? (select the option that most closely represents your own experience)



	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
EFCCA Overall	38	20	14	9.7	5	4	2	8	4435

Gender	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Male	43	20	13	8.3	4	3	1	7	1477
Female	35	20	15	10.5	5	5	2	9	2947
Not Stated	17	33	17	0.0	8	0	25		12



Q37: During your current or most recent period NOT experiencing a flare, how many days in a week do/did you experience cramping pain in your abdomen? (select the option that most closely represents your own experience)

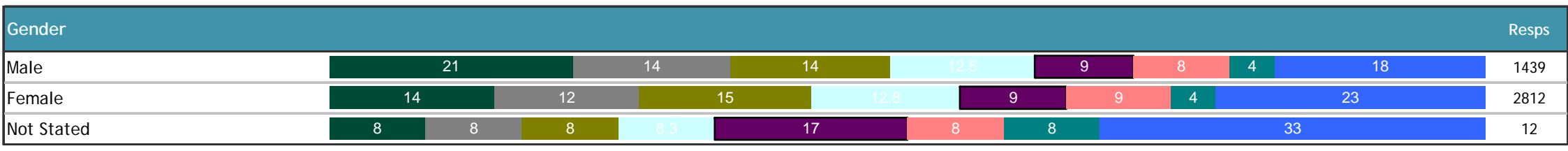
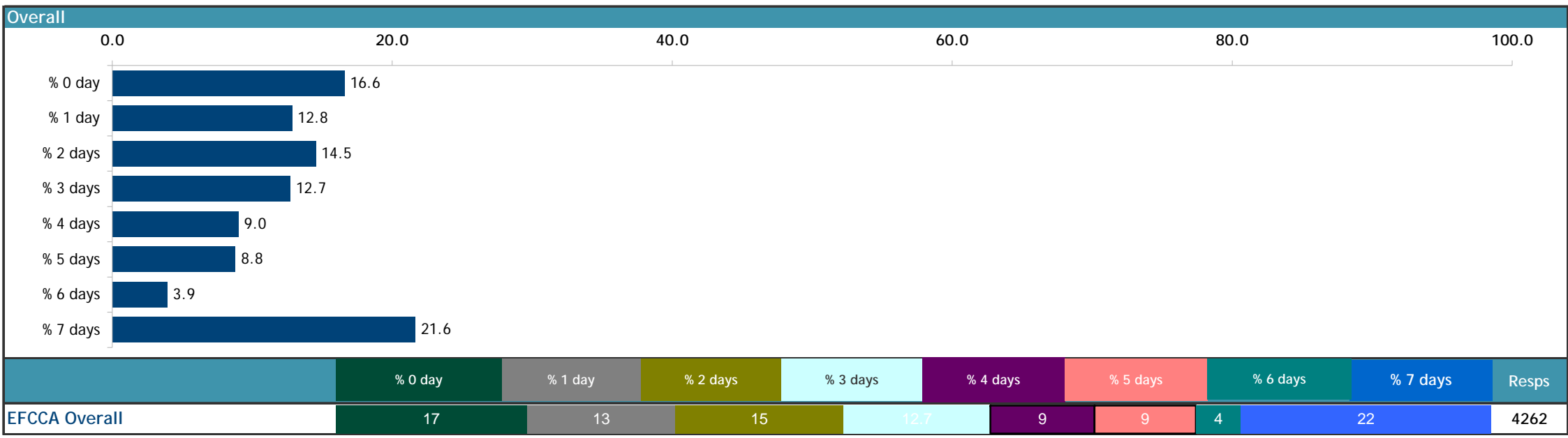
Age Group	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
<18 yrs	36	21	14	11	4	4	2	8	152
19-34	35	22	15	10	4	4	2	8	1920
35-54	38	19	14	9	5	4	2	9	1917
55+	45	15	14	7	6	4	1	8	441

Employment and Disability Status	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Fully employed	44	22	13	8	4	3	1	6	2149
Under-employed due to IBD	26	16	21	12	5	7	2	12	433
Un-employed due to IBD	21	15	16	14	7	6	5	16	357
Student	39	21	14	11	5	4	1	5	644
Retired	44	20	12	8	6	1	1	8	244
Disabled	30	18	13	13	5	5	3	12	612
Seeking disability	27	22	11	11	5	8	3	13	170
Unable to receive disability status	25	15	19	13	6	5	1	14	299
Other	38	19	16	7	5	4	2	9	438
N/A	39	18	14	14	6	4	1	5	181

Type of IBD	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Ulcerative colitis	45	18	13	9	4	4	1	6	1474
Crohn's Disease	35	21	14	10	5	4	2	9	2758
Indeterminate Colitis	25	19	23	8	8	6	2	9	106
Microscopic/collagenous colitis	17	17	33	6	22	0	0	6	18
Not yet confirmed	31	22	16	10	4	2	0	14	49
Other	24	29	12	12	6	6	0	12	17



Q38: During your current or most recent period NOT experiencing a flare, how many days in a week do/did you feel tired, weak or worn out? (select the option that most closely represents your own experience)





Q38: During your current or most recent period NOT experiencing a flare, how many days in a week do/did you feel tired, weak or worn out? (select the option that most closely represents your own experience)

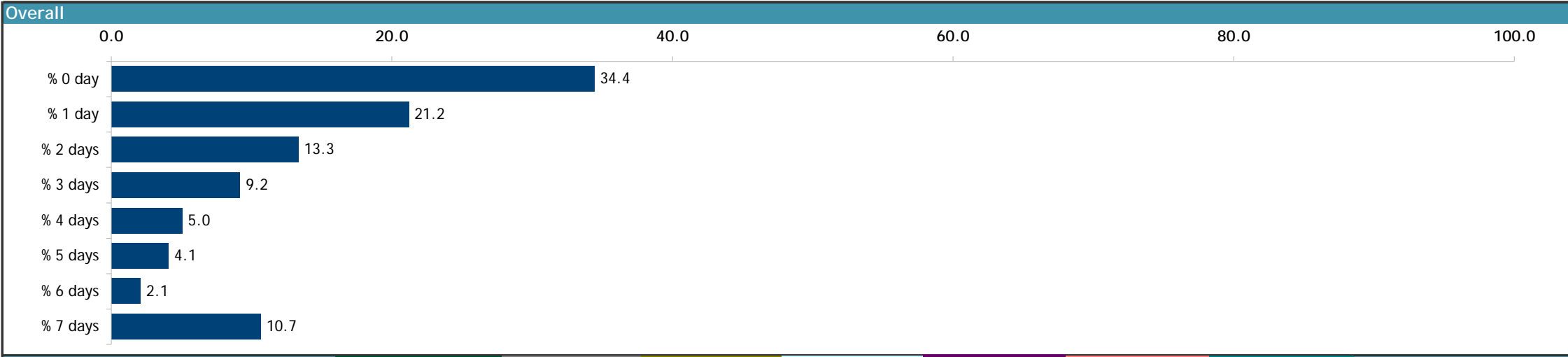
Age Group	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
<18 yrs	26	13	14	17	3	11	5	12	150
19-34	15	15	15	14	10	9	4	18	1859
35-54	17	12	14	12	8	9	4	25	1826
55+	20	9	14	10	9	7	5	26	423

Employment and Disability Status	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Fully employed	20	16	16	13	8	8	3	17	2087
Under-employed due to IBD	7	7	14	14	10	12	7	30	410
Un-employed due to IBD	5	5	12	13	9	9	5	42	338
Student	19	16	18	13	9	8	4	14	627
Retired	19	10	19	14	9	5	2	22	231
Disabled	8	8	11	14	10	10	6	34	572
Seeking disability	9	9	14	12	9	11	6	30	161
Unable to receive disability status	6	5	12	15	12	11	5	34	283
Other	17	15	13	12	9	8	5	21	419
N/A	27	6	13	10	8	11	5	20	177

Type of IBD	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Ulcerative colitis	22	15	13	11	8	8	4	19	1434
Crohn's Disease	14	12	15	14	10	9	4	23	2633
Indeterminate Colitis	10	16	13	12	8	10	6	26	102
Microscopic/collagenous colitis	6	6	25	25	6	13	6	13	16
Not yet confirmed	13	10	19	6	8	8	4	31	48
Other	6	6	25	19	19	6	0	19	16



Q39: During your current or most recent period NOT experiencing a flare, how many days in a week do/did you feel you a sudden, uncontrollable urge for a bowel movement? (select the option that most closely represents your own experience)



	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
EFCCA Overall	34	21	13	9.2	5	4	2	11	4460

Gender	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Male	35	22	12	10	6	3	2	11	1491
Female	34	21	14	9	5	4	2	11	2960
Not Stated	20	20	10	0	10	10	10	20	10



Q39: During your current or most recent period NOT experiencing a flare, how many days in a week do/did you feel you a sudden, uncontrollable urge for a bowel movement? (select the option that most closely represents your own experience)

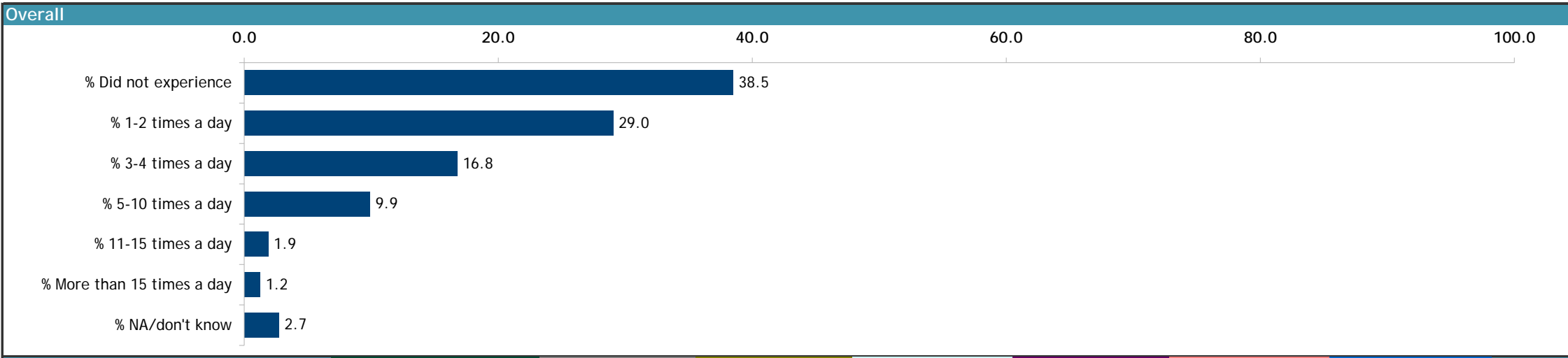
Age Group	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
<18 yrs	53	15	10	6	4	2	1	9	156
19-34	36	24	14	8	5	4	2	8	1932
35-54	32	20	13	10	6	4	2	12	1928
55+	30	17	13	10	4	5	3	18	440

Employment and Disability Status	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Fully employed	37	23	13	9	5	3	2	8	2158
Under-employed due to IBD	29	21	13	9	7	6	2	12	437
Un-employed due to IBD	23	20	12	11	4	7	4	19	361
Student	43	22	13	8	3	3	2	7	648
Retired	31	14	16	11	5	4	4	15	244
Disabled	23	16	13	10	9	7	2	20	610
Seeking disability	22	15	12	16	6	6	5	18	171
Unable to receive disability status	20	18	15	14	8	8	3	14	305
Other	37	21	13	8	5	4	2	11	441
N/A	35	23	11	11	5	2	4	9	182

Type of IBD	% 0 day	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6 days	% 7 days	Resps
Ulcerative colitis	39	22	12	9	4	3	2	9	1478
Crohn's Disease	32	21	14	9	6	5	2	11	2778
Indeterminate Colitis	35	16	12	15	7	5	1	10	107
Microscopic/collagenous colitis	24	35	12	12	0	6	0	12	17
Not yet confirmed	45	16	14	2	8	4	2	8	49
Other	47	18	18	6	0	0	0	12	17



Q40: During your current or most recent period NOT experiencing a flare, how many runny stools or episodes of diarrhoea do/did you experience in the course of a typical day? (select the option that most closely represents your own experience)



	% Did not experience	% 1-2 times a day	% 3-4 times a day	% 5-10 times a day	% 11-15 times a day	% More than 15 times a day	% NA/don't know	Resps
EFCCA Overall	38	29	17	10	2	1	3	4608

Gender	% Did not experience	% 1-2 times a day	% 3-4 times a day	% 5-10 times a day	% 11-15 times a day	% More than 15 times a day	% NA/don't know	Resps
Male	39	29	17	11	2	1	3	1530
Female	38	29	17	9	2	1	3	3066
Not Stated	25	25	33	8	0	0	8	12



Q40: During your current or most recent period NOT experiencing a flare, how many runny stools or episodes of diarrhoea do/did you experience in the course of a typical day? (select the option that most closely represents your own experience)

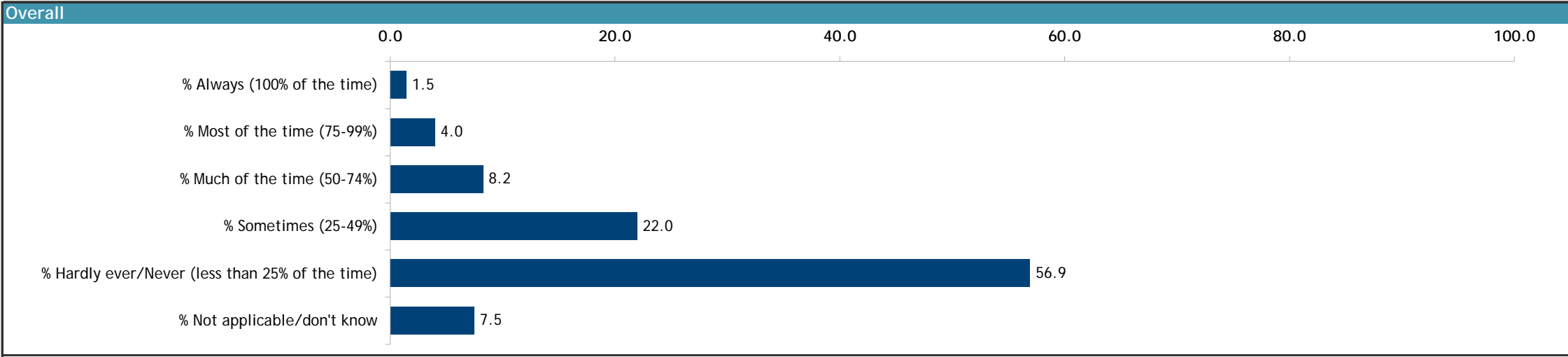
Age Group	% Did not experience	% 1-2 times a day	% 3-4 times a day	% 5-10 times a day	% 11-15 times a day	% More than 15 times a day	% NA/don't know	Resps
<18 yrs	47	33	7	6	1	6	160	
19-34	45	29	14	7	2	1	2	1982
35-54	34	29	19	12	2	1	3	2001
55+	28	26	22	16	2	2	2	460

Employment and Disability Status	% Did not experience	% 1-2 times a day	% 3-4 times a day	% 5-10 times a day	% 11-15 times a day	% More than 15 times a day	% NA/don't know	Resps
Fully employed	42	31	15	7	1	1	2	2200
Under-employed due to IBD	28	31	20	14	3	2	3	457
Un-employed due to IBD	26	25	23	16	4	3	3	382
Student	53	25	12	5	1	0	4	665
Retired	24	29	21	14	4	3	4	256
Disabled	23	22	24	18	5	3	4	640
Seeking disability	24	30	16	19	5	3	2	182
Unable to receive disability status	24	31	22	18	2	0	2	323
Other	39	29	17	9	1	1	4	458
N/A	41	28	16	9	1	1	4	191

Type of IBD	% Did not experience	% 1-2 times a day	% 3-4 times a day	% 5-10 times a day	% 11-15 times a day	% More than 15 times a day	% NA/don't know	Resps
Ulcerative colitis	48	26	12	8	1	1	3	1518
Crohn's Disease	33	31	19	11	2	1	2	2882
Indeterminate Colitis	42	28	13	8	3	1	6	108
Microscopic/collagenous colitis	33	17	28	17	0	0	6	18
Not yet confirmed	54	22	10	6	0	0	8	50
Other	50	22	17	6	0	0	6	18



Q41: During your current or most recent period NOT experiencing a flare, do/did you find that you frequently have/had to abruptly stop or leave a conversation, meeting or activity to deal with symptoms of your bowel disease?



	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
EFCCA Overall	1.4	8.2	22.0	56.9	7.5		4609

Gender	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
Male	2.0	4.0	8.2	21.0	57.0	8.0	1532
Female	1.0	4.0	9.0	22.0	57.0	7.0	3065
Not Stated		8.0	17.0	33.0	33.0	8.0	12



Q41: During your current or most recent period NOT experiencing a flare, do/did you find that you frequently have/had to abruptly stop or leave a conversation, meeting or activity to deal with symptoms of your bowel disease?

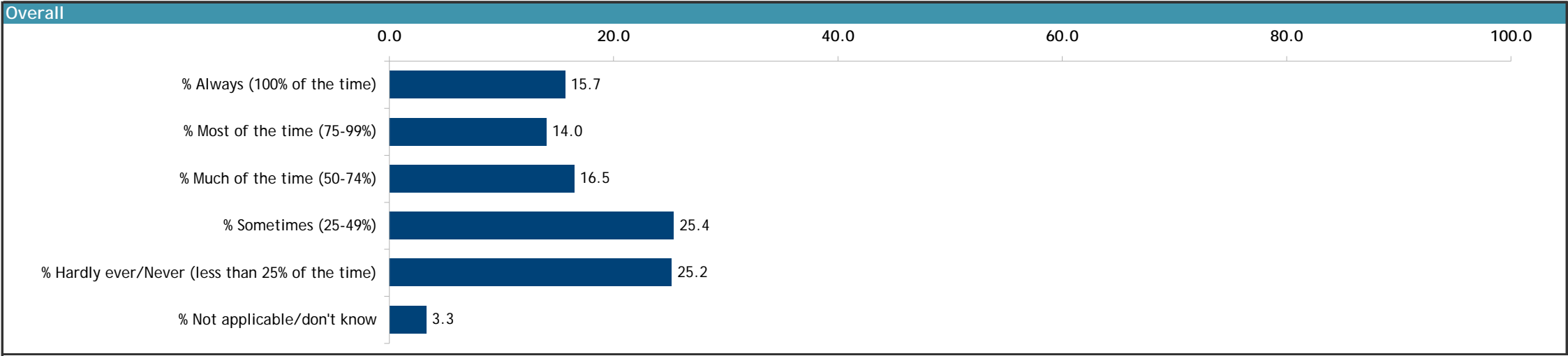
Age Group	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
<18 yrs	2	4	6	18	59	11	160
19-34	1	4	6	20	61	7	1984
35-54	2	4	10	23	55	7	2000
55+	2	7	10	27	44	10	460

Employment and Disability Status	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
Fully employed	2	6	20	63	8	2203	
Under-employed due to IBD	2	4	11	28	51	4	458
Un-employed due to IBD	4	11	17	29	35	5	383
Student	3	6	15	67	8	667	
Retired	2	6	11	30	43	8	255
Disabled	3	7	15	28	40	6	642
Seeking disability	4	12	14	30	35	5	181
Unable to receive disability status	2	8	16	29	39	5	323
Other	1	4	7	21	57	9	456
N/A	1	6	3	16	57	16	190

Type of IBD	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
Ulcerative colitis	1	3	6	19	62	8	1517
Crohn's Disease	2	4	9	23	54	7	2884
Indeterminate Colitis	2	5	6	24	58	5	108
Microscopic/collagenous colitis				44	44	11	18
Not yet confirmed	2	4	6	16	62	10	50
Other	6	17	17	61	0	18	



Q42: During your current or most recent period NOT experiencing a flare, how often do/did you worry about when the next flare will strike?



	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
EFCCA Overall	16	14	16	25	25	3	4607

Gender	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
Male	16	13	16	25	27	3	1532
Female	16	14	17	26	24	3	3063
Not Stated		42	8	8	33	8	12



Q42: During your current or most recent period NOT experiencing a flare, how often do/did you worry about when the next flare will strike?

Age Group	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
<18 yrs	16	10	16	24	22	12	160
19-34	17	15	19	26	21	2	1987
35-54	14	14	15	25	29	3	1997
55+	17	11	13	24	29	6	458

Employment and Disability Status	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
Fully employed	13	13	16	27	28	3	2204
Under-employed due to IBD	19	15	21	27	16	2	456
Un-employed due to IBD	30	18	17	19	14	2	383
Student	16	12	18	26	24	4	668
Retired	17	10	13	23	32	4	253
Disabled	18	16	15	23	25	3	637
Seeking disability	34	17	21	16	10	3	182
Unable to receive disability status	23	22	17	24	12	2	323
Other	13	14	16	27	27	3	455
N/A	15	10	14	21	34	6	192

Type of IBD	% Always (100% of the time)	% Most of the time (75-99%)	% Much of the time (50-74%)	% Sometimes (25-49%)	% Hardly ever/Never (less than 25% of the time)	% Not applicable/don't know	Resps
Ulcerative colitis	17	13	16	26	24	3	1517
Crohn's Disease	14	14	17	25	26	3	2882
Indeterminate Colitis	24	15	13	24	21	3	108
Microscopic/collagenous colitis	11	28	17	22	17	6	18
Not yet confirmed	26	16	14	28	10	6	50
Other	33	22	0	11	28	6	18

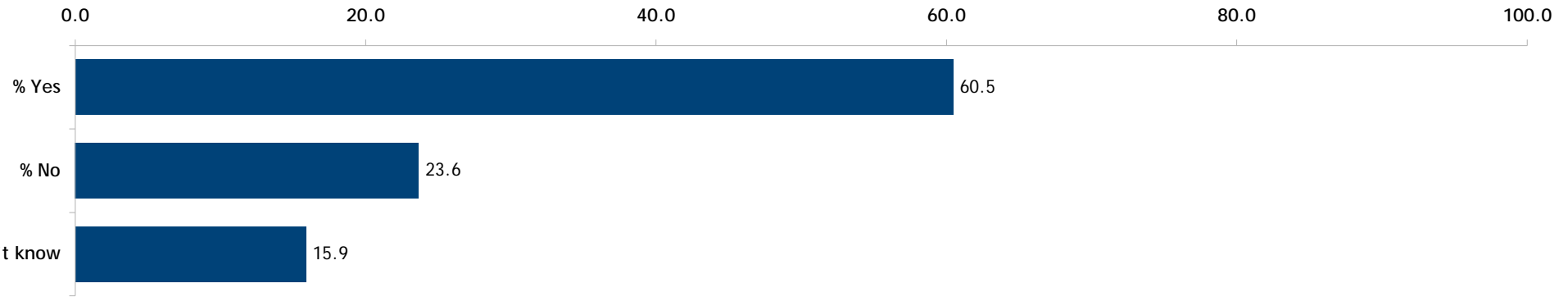


Section D : Overall Work IMPACT



Q43: Do you feel stressed or pressured about sick time from work due to IBD?

Overall



	% Yes	% No	% Not applicable/don't know	% Yes	Resps
EFCCA Overall	60	24	16	60.5	4597

Gender

	% Yes	% No	% Not applicable/don't know	% Yes	Resps
Male	59	27	14	59.1	1524
Female	61	22	17	61.2	3061
Not Stated	42	17	42	41.7	12

Scale : 3 = Yes, 2 = No, 1 = Not applicable/don't know



Q43: Do you feel stressed or pressured about sick time from work due to IBD?

Age Group	% Yes	% No	% Not applicable/don't know	% Yes	Resps
<18 yrs	50	19	31	49.7	159
19-34	67	22	11	66.9	1981
35-54	59	26	15	58.6	1996
55+	45	24	32	44.5	456

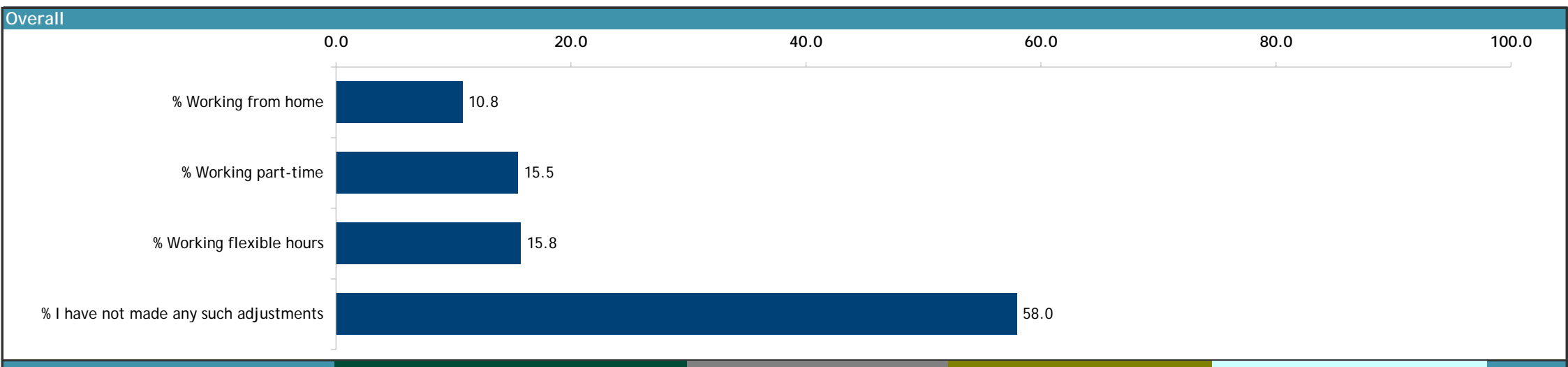
Employment and Disability Status	% Yes	Resps
Fully employed	63	2201
Under-employed due to IBD	82	457
Un-employed due to IBD	65	379
Student	65	665
Retired	36	251
Disabled	60	646
Seeking disability	76	182
Unable to receive disability status	76	318
Other	53	455
N/A	34	189

Type of IBD	% Yes	Resps
Ulcerative colitis	60	1513
Crohn's Disease	60	2878
Indeterminate Colitis	70	108
Microscopic/collagenous colitis	50	18
Not yet confirmed	65	49
Other	50	18

Scale : 3 = Yes, 2 = No, 1 = Not applicable/don't know



Q44: Please indicate any adjustments you have made to your working life, purely to avoid the need to take sick days as a result of your IBD:



	% Working from home	% Working part-time	% Working flexible hours	% I have not made any such adjustments	Resps
EFCCA Overall	11	16	16	58	4417

Gender	% Working from home	% Working part-time	% Working flexible hours	% I have not made any such adjustments	Resps
Male	11	10	18	61	1481
Female	10	19	15	56	2924
Not Stated	17	8	8	67	12



Q44: Please indicate any adjustments you have made to your working life, purely to avoid the need to take sick days as a result of your IBD:

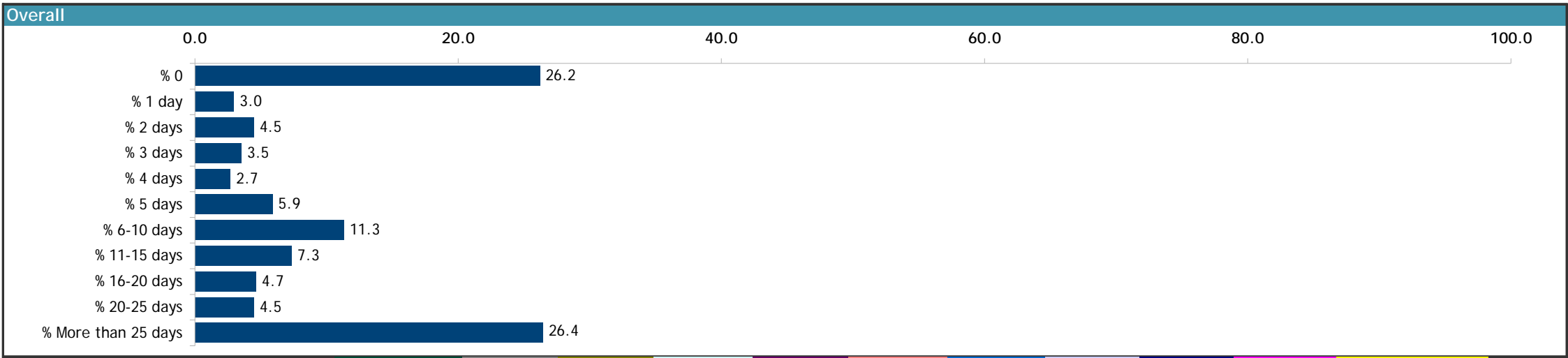
Age Group	% Working from home		% Working part-time	% Working flexible hours	% I have not made any such adjustments	Resps
<18 yrs	8	7	8	77		146
19-34	9	15	17	59		1932
35-54	12	17	16	55		1907
55+	13	13	13	61		427

Employment and Disability Status	% Working from home		% Working part-time	% Working flexible hours	% I have not made any such adjustments	Resps
Fully employed	7	5	18	69		2192
Under-employed due to IBD	13		56	15	16	455
Un-employed due to IBD	24		22	10	44	328
Student	10	11	17	62		639
Retired	12	8	12	68		228
Disabled	13	21	19	47		574
Seeking disability	13	21	16	49		164
Unable to receive disability status	21		39	13	28	301
Other	15	23	14	49		437
N/A	12	13	11	63		177

Type of IBD	% Working from home		% Working part-time	% Working flexible hours	% I have not made any such adjustments	Resps
Ulcerative colitis	11	12	16	61		1467
Crohn's Disease	11	17	15	57		2746
Indeterminate Colitis	13	20	17	50		107
Microscopic/collagenous colitis		24	24	53		17
Not yet confirmed	14	10	18	57		49
Other	11	11	17	61		18



Q45: In the past year, how many days have you been absent from work for reasons related to your IBD?



	% 0	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6-10 days	% 11-15 days	% 16-20 days	% 20-25 days	% More than 25 days	Resps
EFCCA Overall	26	3	4	4	3	6	11	7	5	4	26	4426

Gender	% 0	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6-10 days	% 11-15 days	% 16-20 days	% 20-25 days	% More than 25 days	Resps
Male	26	3	5	4	3	6	12	7	5	6	25	1483
Female	26	3	4	3	3	6	11	8	5	4	27	2931
Not Stated	33	8	0	8	0	8	8	17	0	8	8	12



Q45: In the past year, how many days have you been absent from work for reasons related to your IBD?

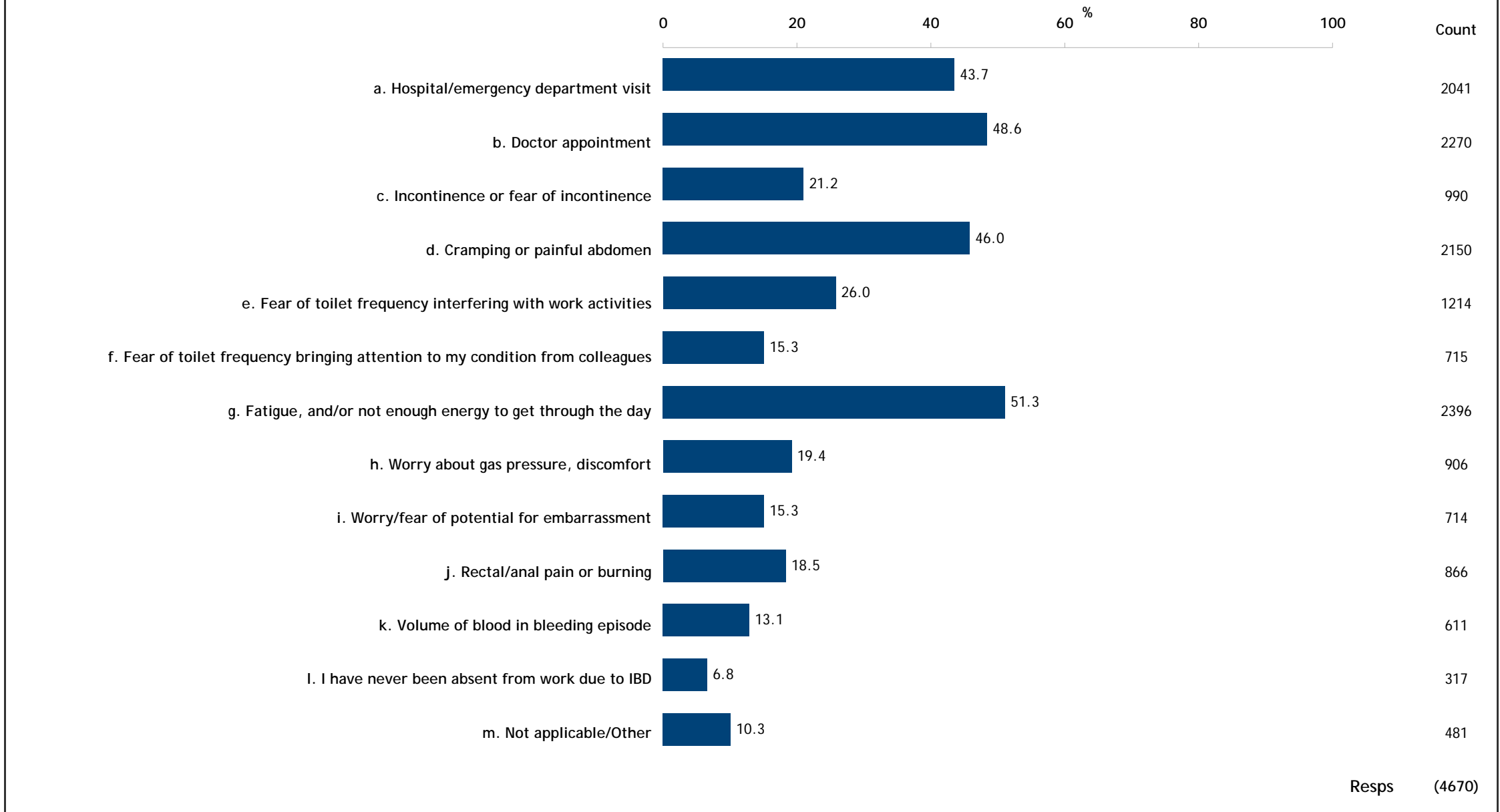
Age Group	% 0	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6-10 days	% 11-15 days	% 16-20 days	% 20-25 days	% More than 25 days	Resps
<18 yrs	17	1	4	2	3	3	13	9	9	5	34	151
19-34	20	3	5	4	3	7	13	8	5	5	26	1933
35-54	28	3	5	3	2	6	11	7	4	4	27	1913
55+	48	2	2	3	3	3	7	3	4	3	22	424

Employment and Disability Status	% 0	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6-10 days	% 11-15 days	% 16-20 days	% 20-25 days	% More than 25 days	Resps
Fully employed	24	5	6	5	3	8	13	9	5	4	18	2196
Under-employed due to IBD	10	1	2	2	3	5	13	11	6	5	43	454
Un-employed due to IBD	15	0	1	1	2	6	4	5	4	62	335	
Student	22	2	6	4	3	7	13	9	5	6	23	645
Retired	62	2	0	1	1	2	4	2	3	2	19	217
Disabled	26	11	2	1	3	8	6	5	5	43	576	
Seeking disability	13	0	1	1	2	7	5	5	5	60	169	
Unable to receive disability status	16	1	1	3	2	2	8	5	5	6	50	298
Other	37	1	5	2	3	4	10	4	4	5	25	440
N/A	51	2	2	3	3	3	10	5	3	5	13	177

Type of IBD	% 0	% 1 day	% 2 days	% 3 days	% 4 days	% 5 days	% 6-10 days	% 11-15 days	% 16-20 days	% 20-25 days	% More than 25 days	Resps
Ulcerative colitis	28	5	6	4	3	7	11	7	5	4	23	1468
Crohn's Disease	25	2	4	4	3	6	12	7	5	5	28	2757
Indeterminate Colitis	23	5	2	2	4	6	12	13	6	3	26	104
Microscopic/collagenous colitis	39	0	6	0	6	11	6	0	33	18	18	
Not yet confirmed	31	0	4	2	0	8	8	10	8	8	19	48
Other	28	0	6	0	11	11	6	0	39	18	18	



Q46: If you have been absent from work due to your IBD, what was this primarily due to? (Tick all that apply)





Q46: If you have been absent from work due to your IBD, what was this primarily due to? (Tick all that apply)

Gender	a. Hospital/emergency department visit	b. Doctor appointment	c. Incontinence or fear of incontinence	d. Cramping or painful abdomen	e. Fear of toilet frequency interfering with work activities	f. Fear of toilet frequency bringing attention to my condition from colleagues	g. Fatigue, and/or not enough energy to get through the day	h. Worry about gas pressure, discomfort	i. Worry/fear of potential for embarrassment	j. Rectal/anal pain or burning	k. Volume of blood in bleeding episode	l. I have never been absent from work due to IBD	m. Not applicable/Other	Resps
Male	45.1	50.2	21.6	43.4	24.6	14.9	48.3	19.0	15.4	20.3	14.2	6.8	8.4	1549
Female	43.3	48.2	21.1	47.6	26.9	15.6	53.1	19.7	15.4	17.8	12.6	6.8	11.3	3093
Not Stated	14.3	10.7	10.7	21.4	7.1	7.1	21.4	7.1	3.6	3.6	7.1	0.0	10.7	28
Age Group	a.	b.	c.	d.	e.	f.	g.	h.	i.	j.	k.	l.	m.	Resps
<18 yrs	59.5	62.6	11.7	50.9	18.4	11.7	50.3	13.5	14.1	14.7	10.4	2.5	12.9	163
19-34	49.4	55.2	22.4	51.5	29.9	18.1	55.0	19.8	16.7	19.2	14.7	6.0	6.9	2000
35-54	41.1	45.2	20.4	44.5	23.9	13.8	51.4	19.4	14.4	18.8	12.5	7.5	11.1	2020
55+	26.8	31.9	23.1	29.1	22.1	11.6	36.8	20.1	14.3	16.5	9.9	9.2	20.8	467



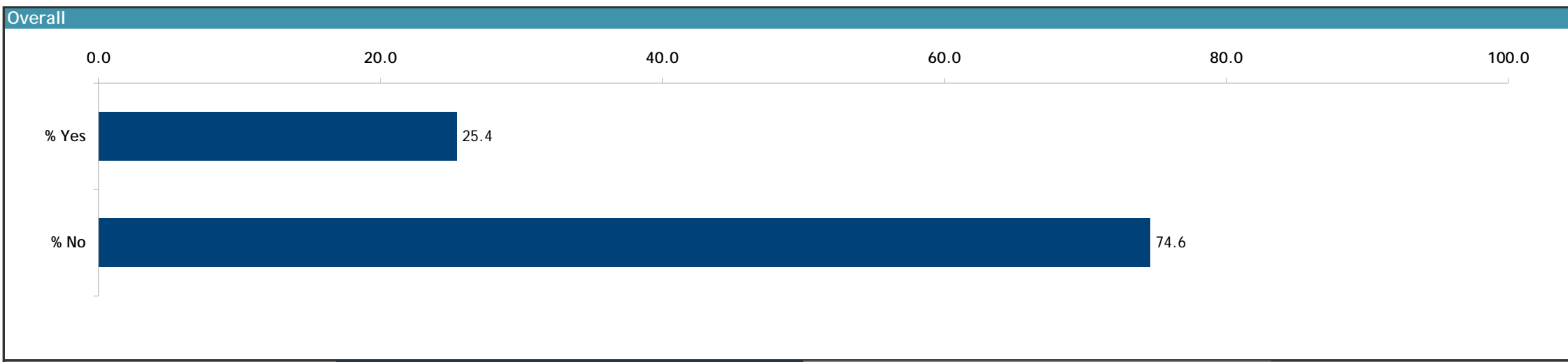
Q46: If you have been absent from work due to your IBD, what was this primarily due to? (Tick all that apply)

Employment and Disability Status	a. Hospital/emergency department visit	b. Doctor appointment	c. Incontinence or fear of incontinence	d. Cramping or painful abdomen	e. Fear of toilet frequency interfering with work activities	f. Fear of toilet frequency bringing attention to my condition from colleagues	g. Fatigue, and/or not enough energy to get through the day	h. Worry about gas pressure, discomfort	i. Worry/fear of potential for embarrassment	j. Rectal/anal pain or burning	k. Volume of blood in bleeding episode	l. I have never been absent from work due to IBD	m. Not applicable/Other	Resps
Fully employed	46.6	55.6	18.8	42.9	23.4	12.8	47.9	16.1	12.1	16.1	13.5	7.9	4.8	2223
Under-employed due to IBD	52.1	47.1	29.6	66.0	32.5	16.8	74.7	24.0	18.7	25.1	18.7	1.7	5.7	459
Un-employed due to IBD	49.6	46.3	35.1	62.5	43.4	30.0	67.2	33.3	30.7	33.1	18.6	1.0	11.9	387
Student	48.3	58.1	21.0	51.0	30.3	18.9	54.2	22.0	17.2	18.9	12.6	5.6	10.0	673
Retired	23.6	29.1	16.7	28.7	17.4	10.1	29.8	15.1	11.6	14.7	7.4	8.9	30.2	258
Disabled	46.4	48.4	29.0	50.4	28.6	18.9	55.5	23.7	17.5	24.0	11.8	2.9	17.7	651
Seeking disability	50.0	52.2	42.4	61.4	41.8	32.1	73.4	35.3	32.6	41.3	23.9	2.7	7.1	184
Unable to receive disability status	45.7	44.1	29.6	61.7	38.6	22.5	70.7	34.0	25.9	34.9	16.7	3.1	13.3	324
Other	38.8	43.0	18.2	42.7	24.7	13.4	49.9	15.6	14.8	16.5	11.3	10.6	15.4	461
N/A	24.1	29.2	14.9	28.2	16.4	10.8	32.8	16.4	15.4	12.8	8.2	12.3	29.7	195

Type of IBD	a.	b.	c.	d.	e.	f.	g.	h.	i.	j.	k.	l.	m.	Resps
Ulcerative colitis	37.5	47.9	27.9	37.6	29.8	17.5	48.7	21.4	18.8	19.4	24.2	9.4	8.5	1535
Crohn's Disease	47.4	49.5	17.2	50.4	23.6	13.8	53.1	18.0	13.0	17.9	7.0	5.4	11.4	2914
Indeterminate Colitis	43.5	50.0	33.3	49.1	32.4	22.2	49.1	25.0	22.2	26.9	25.0	6.5	4.6	108
Microscopic/collagenous colitis	33.3	27.8	33.3	33.3	33.3	27.8	44.4	27.8	22.2	11.1	0.0	5.6	38.9	18
Not yet confirmed	35.3	39.2	25.5	51.0	35.3	15.7	47.1	23.5	25.5	19.6	13.7	9.8	13.7	51
Other	38.9	50.0	16.7	50.0	38.9	33.3	66.7	33.3	27.8	16.7	5.6	5.6	5.6	18



Q47: Have you received or heard of complaints or unfair comments from your superiors and/or colleagues about your performance at work in relation to your illness?



	% Yes	% No	% No	% Diff v. Overall	Resps
EFCCA Overall	25	75	74.6		4338

Gender	% Yes	% No	% No	% Diff v. Overall	Resps
Male	26	74	74.0	-0.8	1451
Female	25	75	74.9	+0.4	2875
Not Stated	25	75	75.0	+0.5	12

Scale : 2 = Yes, 1 = No



Q47: Have you received or heard of complaints or unfair comments from your superiors and/or colleagues about your performance at work in relation to your illness?

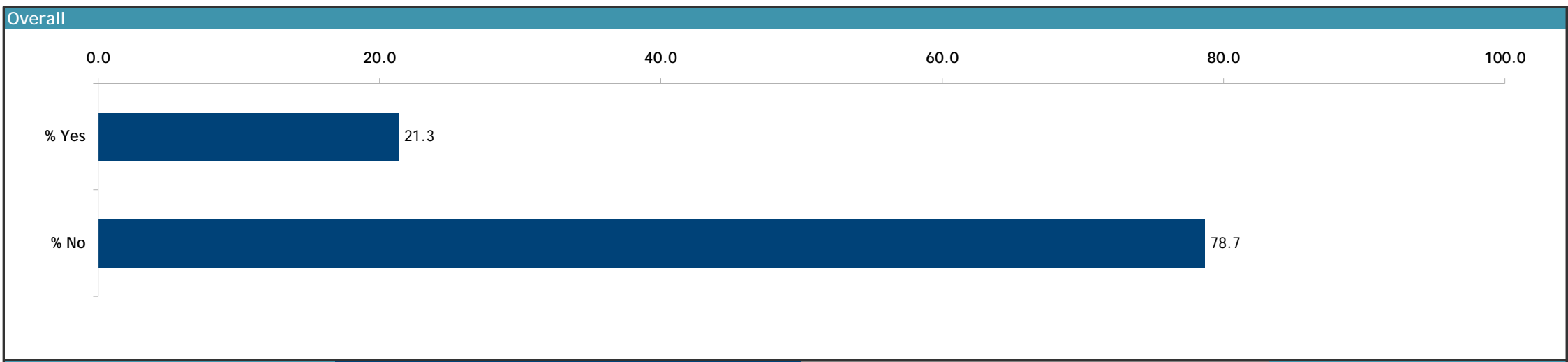
Age Group	% Yes	% No	% No	% Diff v. Overall	Resps
<18 yrs	22	78	77.6	+4.1	143
19-34	26	74	74.2	-0.6	1921
35-54	26	74	73.9	-1.0	1883
55+	21	79	79.0	+5.9	386

Employment and Disability Status	% Yes	% No	% No	% Diff v. Overall	Resps
Fully employed	19	81	80.7	+8.2	2177
Under-employed due to IBD	38	62	62.4	-16.3	439
Un-employed due to IBD	56	44	43.9	-41.2	335
Student	23	77	76.5	+2.6	635
Retired	27	73	73.4	-1.6	203
Disabled	40	60	60.0	-19.6	577
Seeking disability	46	54	53.8	-27.8	169
Unable to receive disability status	43	57	57.3	-23.1	293
Other	21	79	78.8	+5.7	425
N/A	14	86	86.5	+15.9	155

Type of IBD	% Yes	% No	% No	% Diff v. Overall	Resps
Ulcerative colitis	22	78	78.3	+4.9	1437
Crohn's Disease	27	73	72.8	-2.4	2703
Indeterminate Colitis	30	70	70.2	-5.9	104
Microscopic/collagenous colitis	33	67	66.7	-10.6	15
Not yet confirmed	21	79	79.2	+6.1	48
Other	38	63	62.5	-16.2	16



Q48: Do you believe you have been discriminated in the workplace as a direct result of your IBD?



	% Yes	% No	% No	% Diff v. Overall	Resps
EFCCA Overall	21	79	78.7		4301
Gender					
Male	22	78	78.0	-0.9	1443
Female	21	79	79.0	+0.5	2847
Not Stated	27	73	72.7	-7.5	11

Scale : 2 = Yes, 1 = No



Q48: Do you believe you have been discriminated in the workplace as a direct result of your IBD?

Age Group	% Yes	% No	% No	% Diff v. Overall	Resps
<18 yrs	14	86	86.3	+9.8 ↑	139
19-34	21	79	79.2	+0.7	1909
35-54	23	77	76.7	-2.4	1866
55+	17	83	82.7	+5.2 ↑	382

Employment and Disability Status	% Yes	% No	% No	% Diff v. Overall	Resps
Fully employed	16	84	84.4	+7.4 ↑	2160
Under-employed due to IBD	35	65	64.5	-18.0 ↓	437
Un-employed due to IBD	52	48	48.1	-38.9 ↓	335
Student	17	83	82.5	+4.9	630
Retired	19	81	81.0	+3.0	200
Disabled	35	65	64.9	-17.5 ↓	570
Seeking disability	41	59	59.0	-24.9 ↓	166
Unable to receive disability status	40	60	60.1	-23.5 ↓	291
Other	21	79	79.3	+0.8	420
N/A	13	87	87.4	+11.1 ↑	151

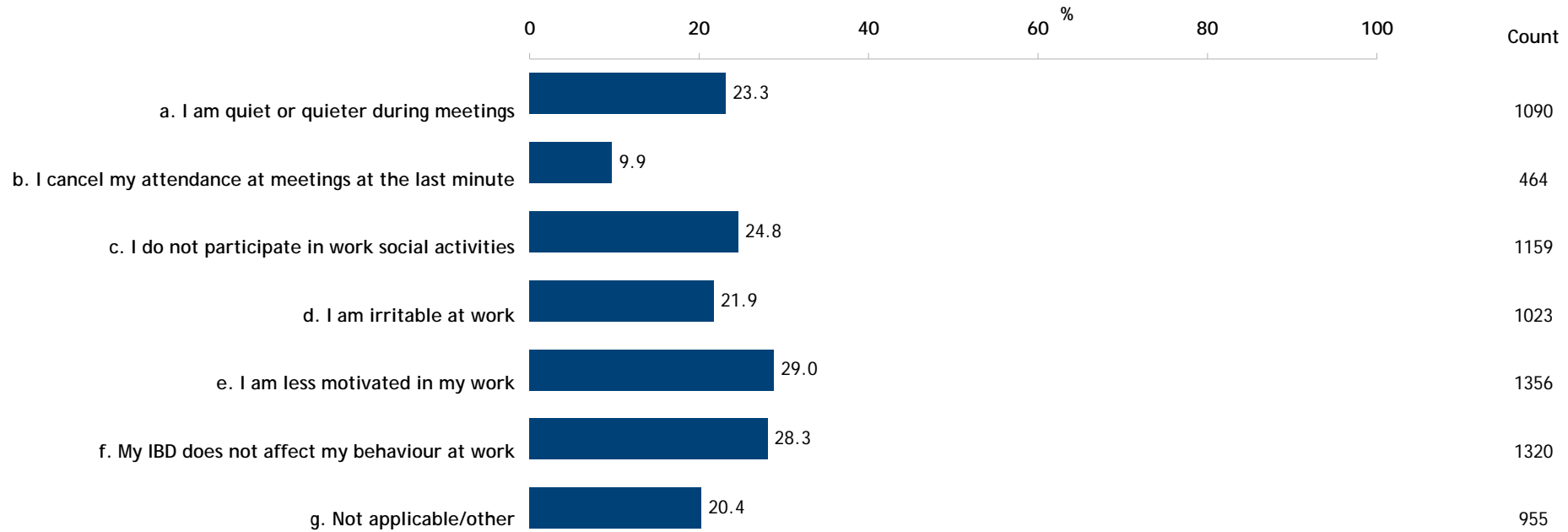
Type of IBD	% Yes	% No	% No	% Diff v. Overall	Resps
Ulcerative colitis	17	83	83.1	+5.7 ↑	1422
Crohn's Disease	23	77	76.8	-2.4	2684
Indeterminate Colitis	27	73	72.5	-7.8 ↓	102
Microscopic/collagenous colitis	27	73	73.3	-6.8 ↓	15
Not yet confirmed	28	72	72.3	-8.0 ↓	47
Other	38	63	62.5	-20.5 ↓	16

Scale : 2 = Yes, 1 = No



Q49:

How does IBD affect your behaviour at work? (Tick all that apply)



Resps (4670)



Q49: How does IBD affect your behaviour at work? (Tick all that apply)

Gender	a. I am quiet or quieter during meetings	b. I cancel my attendance at meetings at the last minute	c. I do not participate in work social activities	d. I am irritable at work	e. I am less motivated in my work	f. My IBD does not affect my behaviour at work	g. Not applicable/other	Resps
Male	25.6	10.9	26.5	24.5	31.6	28.5	16.8	1549
Female	22.4	9.5	24.1	20.8	27.9	28.3	22.3	3093
Not Stated	3.6	7.1	7.1	3.6	14.3	14.3	14.3	28

Age Group	a.	b.	c.	d.	e.	f.	g.	Resps
<18 yrs	22.1	8.0	19.0	12.9	22.1	16.0	37.4	163
19-34	25.3	9.8	24.0	22.4	33.8	30.9	15.8	2000
35-54	22.5	9.7	26.2	22.3	27.2	28.3	21.0	2020
55+	19.9	12.8	25.1	22.3	20.1	21.8	32.5	467



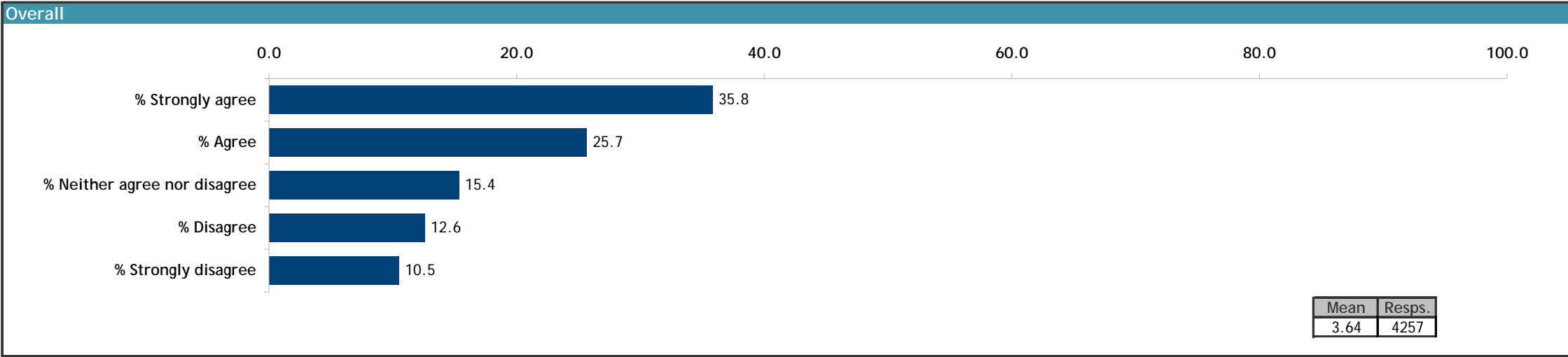
Q49: How does IBD affect your behaviour at work? (Tick all that apply)

Employment and Disability Status	a. I am quiet or quieter during meetings	b. I cancel my attendance at meetings at the last minute	c. I do not participate in work social activities	d. I am irritable at work	e. I am less motivated in my work	f. My IBD does not affect my behaviour at work	g. Not applicable/other	Resps
Fully employed	24.1	8.1	23.0	25.2	30.9	38.1	10.5	2223
Under-employed due to IBD	33.1	17.4	41.8	28.3	41.4	16.1	14.6	459
Un-employed due to IBD	34.6	15.2	39.0	29.7	36.2	10.6	26.6	387
Student	24.8	10.1	22.6	17.1	30.3	27.5	22.7	673
Retired	15.1	9.7	17.4	15.1	16.7	15.1	45.7	258
Disabled	24.0	13.2	28.9	21.7	27.5	17.7	32.9	651
Seeking disability	27.7	21.2	42.4	32.6	43.5	9.2	20.7	184
Unable to receive disability status	32.1	17.6	39.5	26.5	40.1	9.6	25.6	324
Other	18.9	7.4	21.9	16.3	23.4	30.4	29.3	461
N/A	12.3	7.7	11.3	10.8	15.4	26.2	39.5	195

Type of IBD	a.	b.	c.	d.	e.	f.	g.	Resps
Ulcerative colitis	24.2	11.0	28.0	24.2	32.2	28.8	16.8	1535
Crohn's Disease	22.5	9.0	22.6	20.6	27.3	28.8	22.2	2914
Indeterminate Colitis	31.5	13.0	35.2	23.1	31.5	25.9	17.6	108
Microscopic/collagenous colitis	22.2	16.7	33.3	16.7	22.2	11.1	33.3	18
Not yet confirmed	27.5	21.6	39.2	25.5	35.3	7.8	31.4	51
Other	27.8	22.2	27.8	27.8	33.3	22.2	22.2	18



Q50: How much do you agree with the following statements? I believe that IBD has negatively affected my career path, opportunities for advancement, income and/or earning potential



	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
EFCCA Overall	62	15	23	3.64		4257	353

Gender	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
Male	60	16	24	3.60	-1.1	1413	117
Female	62	15	23	3.66	+0.5	2832	235
Not Stated	75	0	25	4.08	+12.3 ↑	12	1

Scale : 5 = Strongly agree, 4 = Agree, 3 = Neither agree nor disagree, 2 = Disagree, 1 = Strongly disagree



Q50: How much do you agree with the following statements? I believe that IBD has negatively affected my career path, opportunities for advancement, income and/or earning potential

Age Group	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
<18 yrs	60	25	15	3.60	-1.1	102	51
19-34	60	16	24	3.59	-1.4	1899	93
35-54	62	15	22	3.67	+0.9	1873	134
55+	65	11	24	3.72	+2.3	378	75

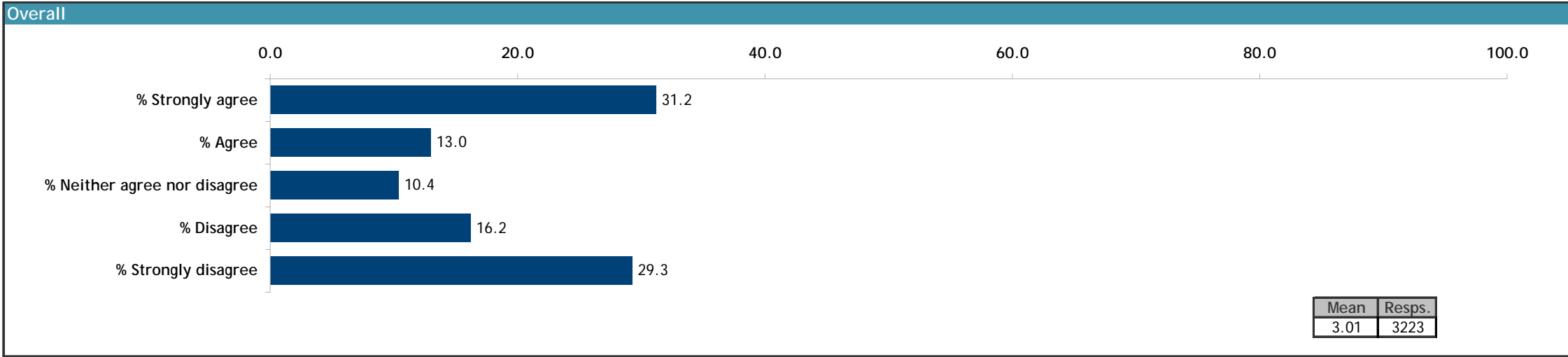
Employment and Disability Status	Mean	% Diff v. Overall	Resps	NA
Fully employed	3.15	-13.4 ↓	2112	110
Under-employed due to IBD	4.39	+20.7 ↑	454	4
Un-employed due to IBD	4.75	+30.6 ↑	370	8
Student	3.53	-2.8	582	85
Retired	4.07	+11.8 ↑	195	52
Disabled	4.33	+19.1 ↑	608	39
Seeking disability	4.39	+20.7 ↑	174	7
Unable to receive disability status	4.60	+26.4 ↑	313	10
Other	3.66	+0.7	421	35
N/A	3.58	-1.4	130	52

Type of IBD	Mean	% Diff v. Overall	Resps	NA
Ulcerative colitis	3.45	-5.1 ↓	1389	129
Crohn's Disease	3.72	+2.3	2684	202
Indeterminate Colitis	3.78	+3.9	104	4
Microscopic/collagenous colitis	3.77	+3.6	13	5
Not yet confirmed	3.85	+5.8 ↑	40	9
Other	3.69	+1.4	16	1

Scale : 5 = Strongly agree, 4 = Agree, 3 = Neither agree nor disagree, 2 = Disagree, 1 = Strongly disagree



Q51: I have lost a job (or had to quit a job) because of my IBD



	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
EFCCA Overall	44	10	45	3.01		3223	1376

Gender	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
Male	42	12	47	2.94	-2.1	1068	459
Female	45	10	45	3.04	+1.0	2148	912
Not Stated	57	0	43	3.29	+9.3 ↑	7	5

Scale : 5 = Strongly agree, 4 = Agree, 3 = Neither agree nor disagree, 2 = Disagree, 1 = Strongly disagree



Q51: I have lost a job (or had to quit a job) because of my IBD

Age Group	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
<18 yrs	23	23	55	2.43	-19.0 ↓	53	99
19-34	42	12	47	2.92	-2.9	1403	588
35-54	46	9	45	3.07	+2.2	1473	528
55+	49	10	41	3.20	+6.3 ↑	292	158

Employment and Disability Status	Mean	% Diff v. Overall	Resps	NA
Fully employed	2.23	-25.8 ↓	1524	689
Under-employed due to IBD	3.72	+23.8 ↑	365	94
Un-employed due to IBD	4.72	+57.1 ↑	347	31
Student	2.81	-6.5 ↓	389	278
Retired	3.72	+23.6 ↑	165	82
Disabled	4.14	+37.8 ↑	510	132
Seeking disability	4.02	+33.7 ↑	147	34
Unable to receive disability status	4.20	+39.7 ↑	260	63
Other	3.11	+3.4	325	128
N/A	2.87	-4.6	90	92

Type of IBD	Mean	% Diff v. Overall	Resps	NA
Ulcerative colitis	2.67	-11.3 ↓	1055	459
Crohn's Disease	3.18	+5.6 ↑	2033	848
Indeterminate Colitis	3.25	+8.2 ↑	79	28
Microscopic/collagenous colitis	3.33	+10.9 ↑	9	9
Not yet confirmed	2.67	-11.3 ↓	27	21
Other	3.08	+2.4	13	4

Scale : 5 = Strongly agree, 4 = Agree, 3 = Neither agree nor disagree, 2 = Disagree, 1 = Strongly disagree

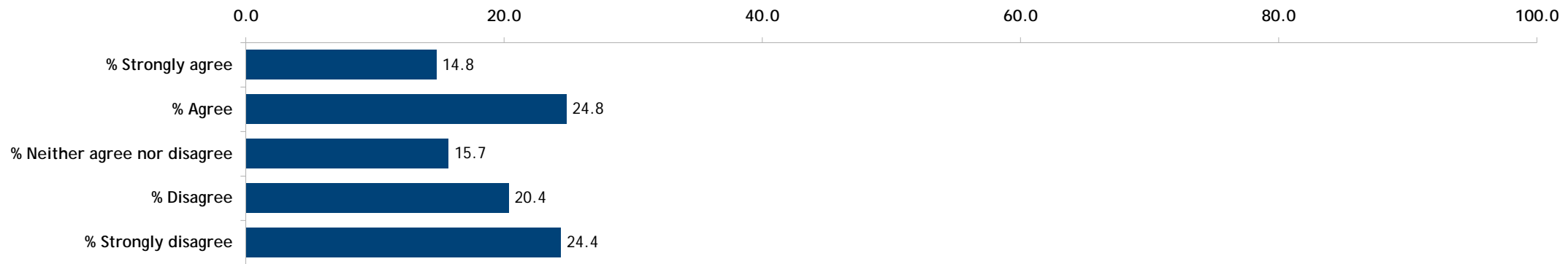


Section E : Overall Life IMPACT



Q52: My IBD has prevented me from pursuing intimate relationship(s)

Overall



Mean	Resps.
2.85	4086

	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
EFCCA Overall	40	16	45	2.85		4086	552

Gender	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
Male	38	15	47	2.79	-2.2	1344	194
Female	40	16	44	2.88	+1.1	2730	358
Not Stated	42	25	33	2.92	+2.3	12	0

Scale : 5 = Strongly agree, 4 = Agree, 3 = Neither agree nor disagree, 2 = Disagree, 1 = Strongly disagree



Q52: My IBD has prevented me from pursuing intimate relationship(s)

Age Group	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
<18 yrs	36	27	36	2.87	+0.6	77	78
19-34	39	16	45	2.84	-0.5	1826	170
35-54	40	15	46	2.85	+0.0	1795	222
55+	42	16	42	2.92	+2.5	384	82

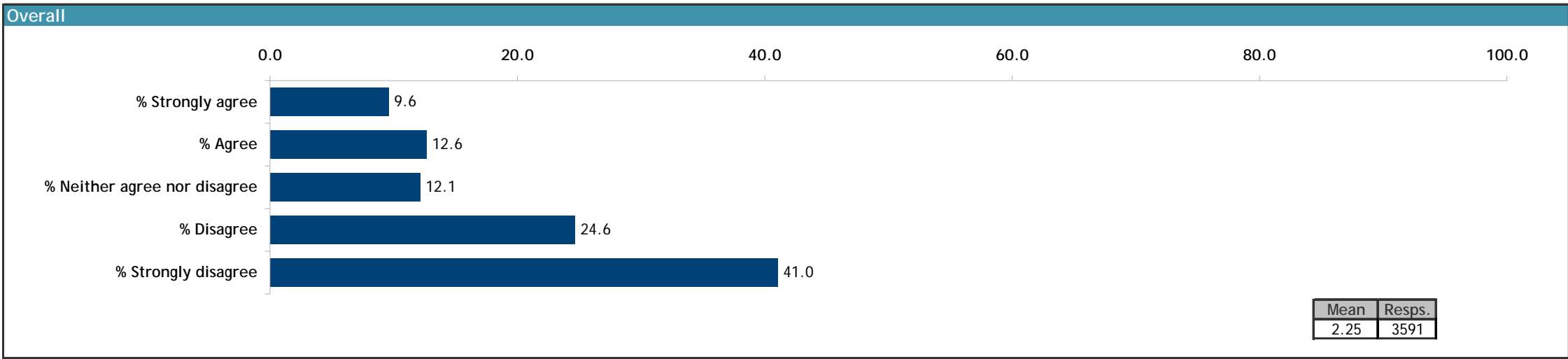
Employment and Disability Status	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
Fully employed	35	14	51	2.67	-6.5 ↓	2009	211
Under-employed due to IBD	51	13	36	3.20	+12.2 ↑	415	43
Un-employed due to IBD	58	19	24	3.56	+24.7 ↑	351	35
Student	40	17	43	2.87	+0.5	570	99
Retired	40	17	43	2.90	+1.7	212	46
Disabled	53	17	30	3.30	+15.6 ↑	573	77
Seeking disability	53	17	30	3.37	+18.1 ↑	165	18
Unable to receive disability status	52	15	33	3.31	+16.2 ↑	290	34
Other	39	18	43	2.85	0.0	391	68
N/A	31	15	54	2.54	-10.9 ↓	144	46

Type of IBD	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
Ulcerative colitis	37	16	46	2.79	-2.3	1350	177
Crohn's Disease	40	15	45	2.87	+0.5	2557	345
Indeterminate Colitis	45	18	37	3.09	+8.4 ↑	98	10
Microscopic/collagenous colitis	64	21	14	3.86	+35.2 ↑	14	4
Not yet confirmed	50	19	31	3.24	+13.5 ↑	42	9
Other	44	13	44	2.63	-8.0 ↓	16	2

Scale : 5 = Strongly agree, 4 = Agree, 3 = Neither agree nor disagree, 2 = Disagree, 1 = Strongly disagree



Q53: My IBD has caused an intimate relationship to end



	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
EFCCA Overall	22	12	66	2.25		3591	1020

Gender	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
Male	21	14	65	2.24	-0.7	1208	321
Female	23	11	66	2.26	+0.2	2376	694
Not Stated	57	14	29	3.43	+52.3 ↑	7	5

Scale : 5 = Strongly agree, 4 = Agree, 3 = Neither agree nor disagree, 2 = Disagree, 1 = Strongly disagree



Q53: My IBD has caused an intimate relationship to end

Age Group	% Agree			% Neither			% Disagree			Mean	% Diff v. Overall	Resps	NA
<18 yrs	17	19	63							2.21	-2.0	63	93
19-34	22	13	65							2.23	-0.9	1612	384
35-54	22	12	66							2.28	+1.1	1583	413
55+	23	10	67							2.24	-0.5	332	127

Employment and Disability Status	% Agree			% Neither			% Disagree			Mean	% Diff v. Overall	Resps	NA
Fully employed	18	11	71							2.09	-7.4	1788	424
Under-employed due to IBD	30	16	55							2.58	+14.4	361	94
Un-employed due to IBD	41	16	43							2.93	+30.0	303	76
Student	18	14	68							2.12	-5.6	497	172
Retired	25	11	64							2.38	+5.5	192	63
Disabled	37	14	50							2.79	+24.0	503	144
Seeking disability	37	17	46							2.85	+26.5	150	32
Unable to receive disability status	37	13	50							2.79	+23.9	255	66
Other	21	11	68							2.17	-3.7	334	120
N/A	18	11	72							2.04	-9.5	131	59

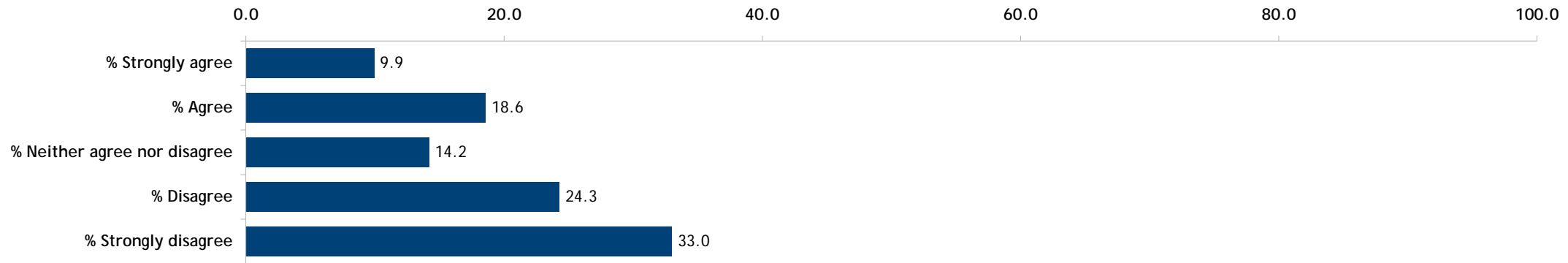
Type of IBD	% Agree			% Neither			% Disagree			Mean	% Diff v. Overall	Resps	NA
Ulcerative colitis	17	13	71							2.08	-7.7	1191	322
Crohn's Disease	25	12	63							2.34	+3.8	2244	646
Indeterminate Colitis	23	13	64							2.35	+4.2	84	23
Microscopic/collagenous colitis	45	0	55							2.73	+21.1	11	7
Not yet confirmed	19	19	61							2.22	-1.3	36	15
Other	27	0	73							2.13	-5.2	15	3

Scale : 5 = Strongly agree, 4 = Agree, 3 = Neither agree nor disagree, 2 = Disagree, 1 = Strongly disagree



Q54: My IBD has prevented me from making new and/or keeping friends.

Overall



Mean	Resps.
2.48	4269

	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
EFCCA Overall	29	14	57	2.48		4269	352

Gender	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
Male	28	13	59	2.46	-1.0	1419	118
Female	29	15	57	2.49	+0.5	2840	232
Not Stated	40	0	60	2.50	+0.8	10	2

Scale : 5 = Strongly agree, 4 = Agree, 3 = Neither agree nor disagree, 2 = Disagree, 1 = Strongly disagree



Q54: My IBD has prevented me from making new and/or keeping friends.

Age Group	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
<18 yrs	27	10	63	2.38	-4.0	139	19
19-34	31	14	56	2.52	+1.5	1887	104
35-54	27	15	58	2.48	-0.2	1839	168
55+	24	14	62	2.37	-4.6	402	59

Employment and Disability Status	Mean	% Diff v. Overall	Resps	NA
Fully employed	2.24	-9.8 ↓	2050	165
Under-employed due to IBD	2.96	+19.2 ↑	430	26
Un-employed due to IBD	3.20	+29.0 ↑	363	18
Student	2.48	+0.0	631	39
Retired	2.48	-0.2	220	34
Disabled	2.98	+20.3 ↑	597	49
Seeking disability	3.10	+24.9 ↑	170	12
Unable to receive disability status	3.04	+22.5 ↑	300	24
Other	2.37	-4.5	413	43
N/A	2.20	-11.3 ↓	164	25

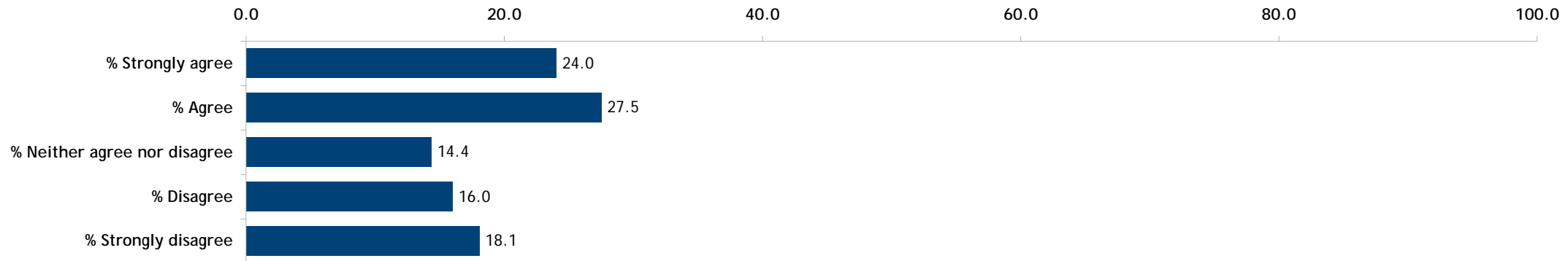
Type of IBD	Mean	% Diff v. Overall	Resps	NA
Ulcerative colitis	2.38	-4.0	1411	113
Crohn's Disease	2.51	+1.1	2669	221
Indeterminate Colitis	2.75	+10.8 ↑	100	7
Microscopic/collagenous colitis	2.85	+14.7 ↑	13	4
Not yet confirmed	3.09	+24.4 ↑	46	5
Other	2.71	+9.0 ↑	17	1

Scale : 5 = Strongly agree, 4 = Agree, 3 = Neither agree nor disagree, 2 = Disagree, 1 = Strongly disagree



Q55: My IBD has negatively affected my ability to perform to my full potential in an educational setting.

Overall



Mean	Resps.
3.23	3986

	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
EFCCA Overall	52	14	34	3.23		3986	639

Gender	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
Male	51	16	34	3.23	+0.0	1357	182
Female	52	14	34	3.23	+0.0	2621	454
Not Stated	50	0	50	3.00	-7.2 ↓	8	3

Scale : 5 = Strongly agree, 4 = Agree, 3 = Neither agree nor disagree, 2 = Disagree, 1 = Strongly disagree



Q55: My IBD has negatively affected my ability to perform to my full potential in an educational setting.

Age Group	% Agree	% Neither	% Disagree	Mean	% Diff v. Overall	Resps	NA
<18 yrs	61	14	25	3.52	+8.8 ↑	145	14
19-34	57	13	31	3.36	+3.8	1805	191
35-54	47	16	37	3.13	-3.2	1705	303
55+	44	15	41	2.98	-8.0 ↓	328	130

Employment and Disability Status	Mean	% Diff v. Overall	Resps	NA
Fully employed	2.87	-11.4 ↓	1932	285
Under-employed due to IBD	3.82	+18.0 ↑	401	55
Un-employed due to IBD	4.17	+28.9 ↑	329	52
Student	3.54	+9.3 ↑	633	40
Retired	3.21	-0.8	182	71
Disabled	3.77	+16.6 ↑	567	80
Seeking disability	3.93	+21.4 ↑	166	14
Unable to receive disability status	4.01	+23.9 ↑	278	45
Other	3.12	-3.6	382	75
N/A	2.97	-8.3 ↓	147	44

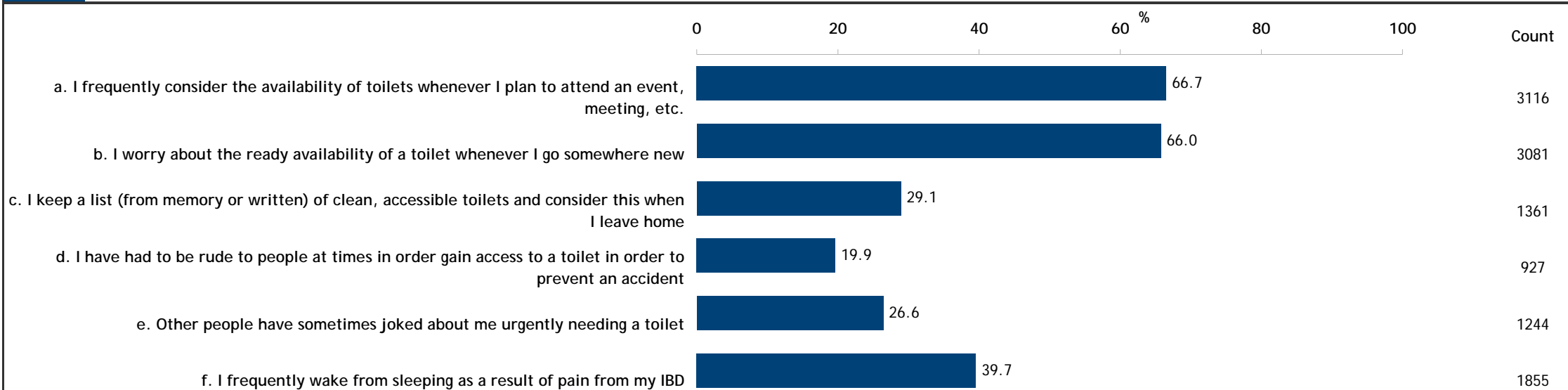
Type of IBD	Mean	% Diff v. Overall	Resps	NA
Ulcerative colitis	3.13	-3.4	1279	243
Crohn's Disease	3.28	+1.3	2526	368
Indeterminate Colitis	3.35	+3.5	98	10
Microscopic/collagenous colitis	4.18	+29.3 ↑	11	7
Not yet confirmed	3.48	+7.5 ↑	42	9
Other	3.53	+9.1 ↑	17	1

Scale : 5 = Strongly agree, 4 = Agree, 3 = Neither agree nor disagree, 2 = Disagree, 1 = Strongly disagree



Q56:

Please tick any of the following that apply to you:



Resps (4670)

Q56: Please tick any of the following that apply to you:

Gender	a. I frequently consider the availability of toilets whenever I plan to attend an event, meeting, etc.	b. I worry about the ready availability of a toilet whenever I go somewhere new	c. I keep a list (from memory or written) of clean, accessible toilets and consider this when I leave home	d. I have had to be rude to people at times in order gain access to a toilet in order to prevent an accident	e. Other people have sometimes joked about me urgently needing a toilet	f. I frequently wake from sleeping as a result of pain from my IBD	Resps
Male	64.7	63.8	27.0	17.7	27.0	33.2	1549
Female	68.1	67.4	30.4	21.1	26.6	43.1	3093
Not Stated	28.6	32.1	10.7	3.6	10.7	25.0	28

Age Group	a.	b.	c.	d.	e.	f.	Resps
<18 yrs	42.3	45.4	15.3	9.2	22.1	34.4	163
19-34	62.8	64.6	25.9	21.2	30.0	42.0	2000
35-54	71.2	68.1	31.9	19.8	25.5	39.7	2020
55+	74.9	72.2	37.0	19.3	19.7	33.2	467



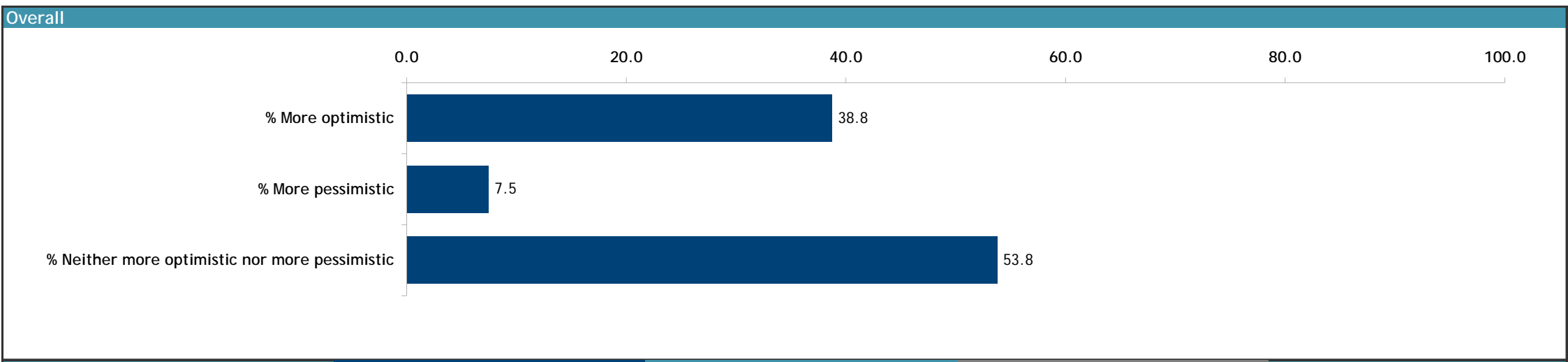
Q56: Please tick any of the following that apply to you:

Employment and Disability Status	a. I frequently consider the availability of toilets whenever I plan to attend an event, meeting, etc.	b. I worry about the ready availability of a toilet whenever I go somewhere new	c. I keep a list (from memory or written) of clean, accessible toilets and consider this when I leave home	d. I have had to be rude to people at times in order gain access to a toilet in order to prevent an accident	e. Other people have sometimes joked about me urgently needing a toilet	f. I frequently wake from sleeping as a result of pain from my IBD	Resps
Fully employed	64.1	62.8	25.8	15.6	23.8	32.7	2223
Under-employed due to IBD	76.7	74.7	39.2	29.4	31.4	55.8	459
Un-employed due to IBD	80.6	79.3	39.8	35.1	43.4	62.3	387
Student	57.2	59.4	25.7	18.6	26.9	39.4	673
Retired	72.5	69.4	34.5	22.1	18.2	35.7	258
Disabled	81.1	76.2	41.8	28.7	32.6	55.8	651
Seeking disability	78.3	82.1	42.9	28.3	43.5	60.9	184
Unable to receive disability status	78.4	79.6	38.3	34.0	38.0	60.8	324
Other	65.3	66.4	26.2	15.8	24.5	34.5	461
N/A	56.9	57.4	20.5	14.9	23.1	29.2	195

Type of IBD	a.	b.	c.	d.	e.	f.	Resps
Ulcerative colitis	69.9	69.3	29.8	20.6	24.3	34.6	1535
Crohn's Disease	65.2	64.1	28.7	19.7	28.0	41.9	2914
Indeterminate Colitis	68.5	72.2	33.3	14.8	25.0	44.4	108
Microscopic/collagenous colitis	72.2	72.2	33.3	22.2	55.6	44.4	18
Not yet confirmed	66.7	74.5	29.4	17.6	21.6	58.8	51
Other	72.2	72.2	38.9	27.8	33.3	55.6	18



Q57: The first time in your life when you met another person with IBD, did you find that this meeting made you feel:



	% More optimistic	% More pessimistic	% Neither more optimistic nor more pessimistic	% Optimistic	Resps
EFCCA Overall	39	7	54	38.8	4425
Gender				% Optimistic	Resps
Male	38	7	55	37.6	1483
Female	39	7	53	39.2	2930
Not Stated	58	33	8	58.3	12

Scale : 3 = More optimistic, 2 = More pessimistic, 1 = Neither more optimistic nor more pessimistic



Q57: The first time in your life when you met another person with IBD, did you find that this meeting made you feel:

Age Group	% More optimistic	% More pessimistic	% Neither more optimistic nor more pessimistic	% Optimistic	Resps
<18 yrs	43	6	52	42.8	145
19-34	43	8	49	42.9	1926
35-54	36	8	56	36.1	1917
55+	30	6	64	30.3	433

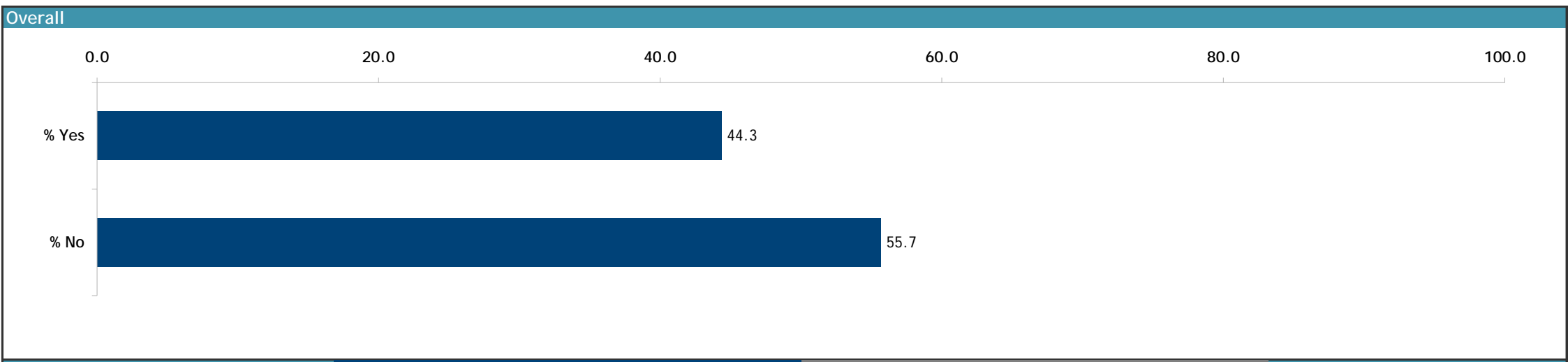
Employment and Disability Status	% More optimistic	% More pessimistic	% Neither more optimistic nor more pessimistic	% Optimistic	Resps
Fully employed	39	7	54	39.2	2143
Under-employed due to IBD	40	9	51	39.8	430
Un-employed due to IBD	38	10	52	37.8	365
Student	46	7	47	45.9	638
Retired	34	6	60	33.6	235
Disabled	35	9	56	35.1	624
Seeking disability	39	10	51	39.0	172
Unable to receive disability status	33	10	57	33.3	306
Other	35	7	59	34.8	437
N/A	38	7	55	38.2	178

Type of IBD	% More optimistic	% More pessimistic	% Neither more optimistic nor more pessimistic	% Optimistic	Resps
Ulcerative colitis	41	6	52	41.5	1444
Crohn's Disease	37	8	54	37.4	2784
Indeterminate Colitis	37	13	50	36.9	103
Microscopic/collagenous colitis	33	0	67	33.3	15
Not yet confirmed	38	0	63	37.5	48
Other	47	6	47	47.1	17

Scale : 3 = More optimistic, 2 = More pessimistic, 1 = Neither more optimistic nor more pessimistic



Q58: Have you engaged in any way with one of our EFCCA member associations?



	% Yes	% No	% Yes	% Diff v. Overall	Resps
EFCCA Overall	44	56	55.7		4521

Gender	% Yes	% No	% Yes	% Diff v. Overall	Resps
Male	43	57	56.6	+1.8	1504
Female	45	55	55.2	-0.9	3006
Not Stated	45	55	54.5	-2.0	11

Scale : 2 = Yes, 1 = No



Q58: Have you engaged in any way with one of our EFCCA member associations?

Age Group	% Yes	% No	% Yes	% Diff v. Overall	Resps
<18 yrs	44	56	56.2	+1.0	153
19-34	39	61	60.8	+9.1	1965
35-54	48	52	52.2	-6.2	1958
55+	52	48	48.2	-13.4	442

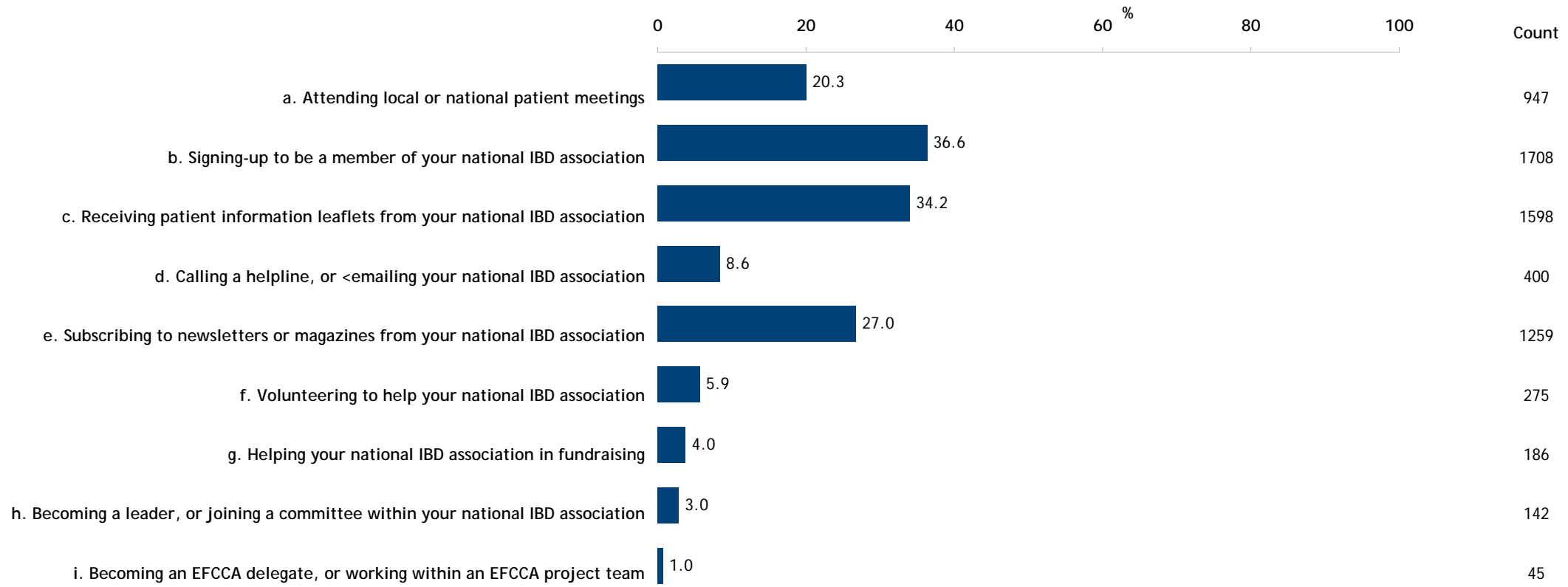
Employment and Disability Status	% Yes	% No	% Yes	% Diff v. Overall	Resps
Fully employed	44	56	55.6	-0.1	2180
Under-employed due to IBD	48	52	52.4	-5.9	435
Un-employed due to IBD	45	55	55.5	-0.3	373
Student	42	58	57.6	+3.5	658
Retired	57	43	43.1	-22.6	246
Disabled	52	48	47.7	-14.3	631
Seeking disability	48	52	52.0	-6.6	173
Unable to receive disability status	49	51	51.4	-7.6	311
Other	40	60	59.9	+7.6	449
N/A	39	61	61.3	+10.1	186

Type of IBD	% Yes	% No	% Yes	% Diff v. Overall	Resps
Ulcerative colitis	45	55	55.0	-1.2	1487
Crohn's Disease	45	55	55.3	-0.6	2828
Indeterminate Colitis	42	58	58.3	+4.8	108
Microscopic/collagenous colitis	28	72	72.2	+29.7	18
Not yet confirmed	27	73	72.9	+31.0	48
Other	28	72	72.2	+29.7	18

Scale : 2 = Yes, 1 = No



Q59: Have you engaged in any way with one of our member associations? If so, what level of involvement do you have? (Tick all that apply)



Resps (4670)



Q59: Have you engaged in any way with one of our member associations? If so, what level of involvement do you have? (Tick all that apply)

Gender	a. Attending local or national patient meetings	b. Signing-up to be a member of your national IBD association	c. Receiving patient information leaflets from your national IBD association	d. Calling a helpline, or e-mailing your national IBD association	e. Subscribing to newsletters or magazines from your national IBD association	f. Volunteering to help your national IBD association	g. Helping your national IBD association in fundraising	h. Becoming a leader, or joining a committee within your national IBD association	i. Becoming an EFCCA delegate, or working within an EFCCA project team	Resps
Male	21.0	35.6	34.0	8.4	26.4	5.5	4.2	3.0	1.0	1549
Female	20.0	37.2	34.5	8.7	27.4	6.1	3.8	3.0	0.9	3093
Not Stated	10.7	17.9	17.9	7.1	10.7	7.1	7.1	7.1	0.0	28

Age Group	a.	b.	c.	d.	e.	f.	g.	h.	i.	Resps
<18 yrs	18.4	31.9	31.9	8.6	25.2	3.7	1.8	1.2	0.0	163
19-34	17.5	31.8	29.5	7.8	23.9	5.8	3.6	2.8	1.0	2000
35-54	21.7	39.9	37.0	8.8	29.8	6.0	4.3	3.1	1.0	2020
55+	27.2	45.8	44.5	11.1	29.6	7.1	5.6	4.7	1.1	467



Q59: Have you engaged in any way with one of our member associations? If so, what level of involvement do you have? (Tick all that apply)

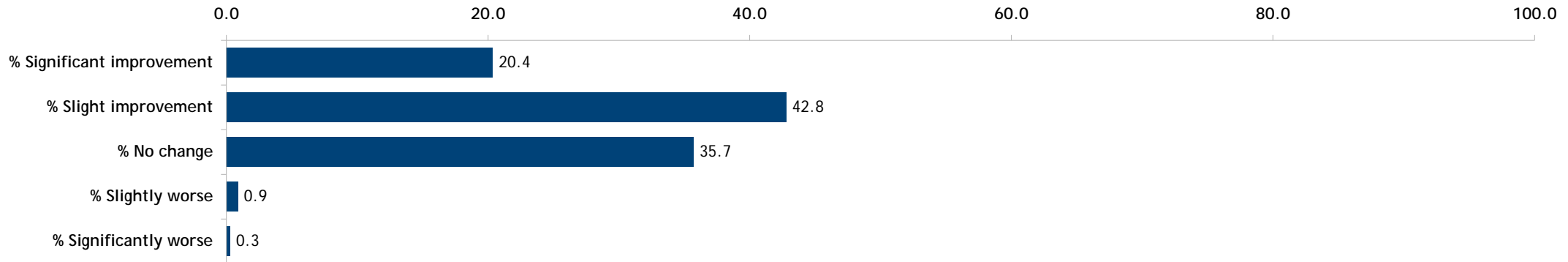
Employment and Disability Status	a. Attending local or national patient meetings	b. Signing-up to be a member of your national IBD association	c. Receiving patient information leaflets from your national IBD association	d. Calling a helpline, or emailing your national IBD association	e. Subscribing to newsletters or magazines from your national IBD association	f. Volunteering to help your national IBD association	g. Helping your national IBD association in fundraising	h. Becoming a leader, or joining a committee within your national IBD association	i. Becoming an EFCCA delegate, or working within an EFCCA project team	Resps
Fully employed	19.9	37.1	34.5	7.8	27.2	6.1	4.6	3.3	1.2	2223
Under-employed due to IBD	23.1	41.0	36.2	12.0	32.0	8.1	4.6	3.9	1.1	459
Un-employed due to IBD	21.2	37.0	36.7	11.4	25.3	5.7	4.9	2.3	0.5	387
Student	18.9	31.8	33.1	8.8	26.0	6.1	3.9	2.7	1.3	673
Retired	30.6	46.1	45.0	9.7	30.6	7.0	4.3	3.9	0.4	258
Disabled	29.3	43.9	40.6	13.2	33.0	9.4	4.5	5.1	1.7	651
Seeking disability	21.7	41.8	40.8	13.6	27.7	8.7	6.0	3.8	1.1	184
Unable to receive disability status	23.8	41.0	39.8	10.2	30.9	5.6	3.7	2.2	0.6	324
Other	18.9	32.1	31.5	10.2	23.4	4.8	3.0	1.7	0.4	461
N/A	16.9	32.3	28.2	3.6	26.2	1.5	0.5	0.5	0.0	195

Type of IBD	a.	b.	c.	d.	e.	f.	g.	h.	i.	Resps
Ulcerative colitis	20.1	37.4	35.5	7.2	27.0	5.1	3.9	2.5	0.8	1535
Crohn's Disease	20.7	36.7	34.1	9.3	27.5	6.3	4.0	3.4	1.1	2914
Indeterminate Colitis	22.2	34.3	36.1	11.1	24.1	5.6	6.5	2.8	0.0	108
Microscopic/collagenous colitis	0.0	27.8	16.7	16.7	11.1	0.0	0.0	0.0	0.0	18
Not yet confirmed	9.8	27.5	17.6	2.0	15.7	5.9	2.0	3.9	2.0	51
Other	22.2	27.8	22.2	11.1	16.7	16.7	5.6	0.0	0.0	18



Q60: If yes, to what degree has being part of a patient's association affected the impact on your life in general as someone with IBD?

Overall



Mean	Resps.
3.82	2176

	% Improvement	% No change	% Worse	Mean	% Diff v. Overall	Resps	NA
EFCCA Overall	63	36	1	3.82		2176	1363

Gender	% Improvement	% No change	% Worse	Mean	% Diff v. Overall	Resps	NA
Male	63	36	1	3.81	-0.2	712	477
Female	63	36	1	3.82	+0.0	1458	883
Not Stated	100	0	0	4.67	+22.1	6	3

Scale : 5 = Significant improvement, 4 = Slight improvement, 3 = No change, 2 = Slightly worse, 1 = Significantly worse



Q60: If yes, to what degree has being part of a patient's association affected the impact on your life in general as someone with IBD?

Age Group	% Improvement	% No change	% Worse	Mean	% Diff v. Overall	Resps	NA
<18 yrs	59	41	0	3.80	-0.6	64	55
19-34	63	36	1	3.80	-0.4	826	658
35-54	64	35	1	3.84	+0.5	1032	529
55+	59	40	1	3.79	-0.7	252	120

Employment and Disability Status	% Improvement	% No change	% Worse	Mean	% Diff v. Overall	Resps	NA
Fully employed	64	35	1	3.82	+0.0	1030	678
Under-employed due to IBD	64	36	1	3.84	+0.4	244	117
Un-employed due to IBD	59	39	2	3.73	-2.3	196	98
Student	63	35	2	3.80	-0.6	289	211
Retired	67	33	1	3.92	+2.7	144	61
Disabled	63	35	1	3.85	+0.7	360	149
Seeking disability	60	40	0	3.79	-0.9	94	48
Unable to receive disability status	64	35	1	3.83	+0.2	170	87
Other	60	39	1	3.75	-1.9	186	147
N/A	61	38	1	3.82	+0.1	74	60

Type of IBD	% Improvement	% No change	% Worse	Mean	% Diff v. Overall	Resps	NA
Ulcerative colitis	66	33	1	3.85	+0.8	714	466
Crohn's Disease	61	37	1	3.80	-0.4	1378	822
Indeterminate Colitis	63	31	6	3.77	-1.3	52	26
Microscopic/collagenous colitis	75	25	0	4.00	+4.7	4	12
Not yet confirmed	71	24	6	3.82	+0.1	17	27
Other	67	33	0	3.83	+0.3	6	7

Scale : 5 = Significant improvement, 4 = Slight improvement, 3 = No change, 2 = Slightly worse, 1 = Significantly worse