**Additional file 3, Table S1: missing data**

**Number and percent of participants with missing data for each measurement, by recruitment method**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Invited****(n=6133)** | **Self-selection****(n=2353)** | **Total****(n=8486)** |
| **Demographic Characteristics, n (%)** |
| Gender | 179 | (2.92) | 115 | (4.89) | 294 | (3.46) |
| Age | 188 | (3.07) | 116 | (4.93) | 304 | (3.58) |
| BMI | 423 | (6.90) | 181 | (7.69) | 604 | (7.12) |
| Employment | 193 | (3.15) | 117 | (4.97) | 310 | (3.65) |
| Education | 212 | (3.46) | 117 | (4.97) | 329 | (3.88) |
| Relationship Status | 212 | (3.46) | 117 | (4.97) | 329 | (3.88) |
| **Lifestyle Characteristics, n (%)** |
| Smoker | 208 | (3.39) | 120 | (5.10) | 328 | (3.87) |
| Alcohol | 210 | (3.42) | 119 | (5.06) | 329 | (3.88) |
| **Clinical Characteristics, n (%)** |
| Diagnosis | 49 | (0.80) | 17 | (0.72) | 66 | (0.78) |
| Operation | 49 | (0.80) | 162 | (6.88) | 211 | (2.49) |
| Stoma | 65 | (1.06) | 24 | (1.02) | 89 | (1.05) |
| Pouch | 78 | (1.27) | 24 | (1.02) | 102 | (1.20) |
| Fistula | 60 | (0.98) | 16 | (0.68) | 76 | (0.90) |
| Biologic medications | 606 | (9.88) | 170 | (7.22) | 76 | (0.90) |
| IBD medications | 62 | (1.01) | 32 | (1.36) | 76 | (0.90) |
| Mental health conditions | 0 | (0.00) | 0 | (0.00) | 0 | (0.00) |
| Physical health conditions | 0 | (0.00) | 0 | (0.00) | 0 | (0.00) |
| Depression (PHQ-9) | 244 | (3.98) | 187 | (7.95) | 431 | (5.08) |
| Anxiety (GAD-7) | 192 | (3.13) | 111 | (4.72) | 303 | (3.57) |
| EQ-5D-5L index | 235 | (3.83) | 130 | (5.52) | 365 | (4.30) |
|  mobility | 213 | (3.47) | 121 | (5.14) | 334 | (3.94) |
|  self-care | 223 | (3.64) | 126 | (5.35) | 349 | (4.11) |
|  usual activities | 225 | (3.67) | 127 | (5.40) | 352 | (4.15) |
|  pain/discomfort | 227 | (3.70) | 127 | (5.40) | 354 | (4.17) |
|  anxiety/depression | 230 | (3.75) | 130 | (5.52) | 360 | (4.24) |
| EQ-5D-5L VAS score | 234 | (3.82) | 135 | (5.74) | 369 | (4.35) |
| PROMIS pain intensity | 163 | (2.66) | 99 | (4.21) | 262 | (3.09) |
| PROMIS fatigue | 298 | (4.86) | 128 | (5.44) | 426 | (5.02) |
| PROMIS incontinence | 581 | (9.47) | 258 | (10.96) | 839 | (9.89) |
| IBD Control | 300 | (4.89) | 130 | (5.52) | 430 | (5.07) |
| IBD Control VAS score | 149 | (2.43) | 81 | (3.44) | 230 | (2.71) |
| IBD Disease Activity |  |  |  |  |  |  |
|  Crohn's Disease, (n=3886) | 410 | (15.06) | 200 | (17.41) | 610 | (15.76) |
|  Ulcerative Colitis, (n=2580) | 292 | (16.25) | 115 | (14.69) | 407 | (15.78) |

**Additional file 3, Table S2: Demographic and lifestyle characteristics by diagnosis**

|  |  |  |  |
| --- | --- | --- | --- |
| **Characteristic** | **Crohn's disease****(n=4168)** | **Other IBD****(n=4252)** | **Totala****(n=8486)** |
| **Gender, n(%)** |  |  |  |  |  |  |
| Male | 1479 | (35.48) | 1785 | (41.98) | 3285 | (38.71) |
| Female | 2550 | (61.18) | 2323 | (54.63) | 4888 | (57.60) |
| Prefer to self-define | 6 | (0.14) | 7 | (0.16) | 13 | (0.15) |
| **Age (years), mean (sd)** | 48.07 | (15.08) | 51.37 | (15.56) | 49.77 | (15.43) |
| **Ethnicity, n(%)** |  |  |  |  |  |  |
| White | 3840 | (92.13) | 3876 | (91.16) | 7751 | (91.34) |
| Mixed | 60 | (1.44) | 58 | (1.36) | 118 | (1.39) |
| Asian | 78 | (1.87) | 130 | (3.06) | 209 | (2.46) |
| Black | 22 | (0.53) | 13 | (0.31) | 35 | (0.41) |
| Other | 24 | (0.58) | 27 | (0.63) | 51 | (0.60) |
| Prefer not to say | 7 | (0.17) | 13 | (0.31) | 20 | (0.24) |
| **Employment, n(%)** |  |  |  |  |  |  |
| Full time | 1695 | (40.67) | 1642 | (38.62) | 3345 | (39.42) |
| Part time | 559 | (13.41) | 559 | (13.15) | 1123 | (13.23) |
| Student | 112 | (2.69) | 93 | (2.19) | 205 | (2.42) |
| Retired | 778 | (18.67) | 1127 | (26.51) | 1921 | (22.64) |
| Unemployed | 119 | (2.86) | 98 | (2.30) | 218 | (2.57) |
| Self-employed | 286 | (6.86) | 312 | (7.34) | 603 | (7.11) |
| Homemaker | 146 | (3.50) | 116 | (2.73) | 262 | (3.09) |
| Unemployed due to illness/disability | 330 | (7.92) | 168 | (3.95) | 499 | (5.88) |
| **Education, n(%)** |  |  |  |  |  |  |
| No formal education | 98 | (2.35) | 118 | (2.78) | 219 | (2.58) |
| Secondary school | 808 | (19.39) | 790 | (18.58) | 1609 | (18.96) |
| Sixth form | 358 | (8.59) | 306 | (7.20) | 668 | (7.87) |
| Further education | 1132 | (27.16) | 1127 | (26.51) | 2270 | (26.75) |
| Higher education | 1621 | (38.89) | 1763 | (41.46) | 3391 | (39.96) |
| **Relationship status, n(%)** |  |  |  |  |  |  |
| Married/civil partnership | 2098 | (50.34) | 2387 | (56.14) | 4507 | (53.11) |
| Living with partner | 658 | (15.79) | 610 | (14.35) | 1272 | (14.99) |
| Widowed | 90 | (2.16) | 110 | (2.59) | 202 | (2.38) |
| Divorced/separated | 218 | (5.23) | 239 | (5.62) | 459 | (5.41) |
| Single | 709 | (17.01) | 579 | (13.62) | 1293 | (15.24) |
| With partner, not living together | 243 | (5.83) | 180 | (4.23) | 424 | (5.00) |
| **Smoker, n(%)** |  |  |  |  |  |  |
| Never smoked | 2072 | (49.71) | 2081 | (48.94) | 4165 | (49.08) |
| Ex-smoker | 1577 | (37.84) | 1866 | (43.89) | 3464 | (40.82) |
| Current smoker | 367 | (8.81) | 159 | (3.74) | 529 | (6.23) |
| **Alcohol (units/week), mean (sd)** | 0.59 | (0.61) | 0.72 | (0.63) | 0.66 | (0.63) |

a **Sixty-six respondents did not provide data on IBD disease type, thus rows do not sum to 8,486**

**Additional file 3, Table S3: Clinical characteristics by diagnosis**

|  |  |  |  |
| --- | --- | --- | --- |
| **Characteristic** | **Crohn’s disease****(n=4168)** | **Other IBD****(n=4252)** | **Totala****(n=8486)** |
| **BMI** (kg/m2) – mean (sd) | 26.80 | (5.99) | 26.89 | (5.79) | 26.85 | (5.89) |
|  Underweight, n(%) | 121 | (2.90) | 73 | (1.72) | 195 | (2.30) |
|  Healthy weight, n(%) | 1625 | (38.99) | 1579 | (37.14) | 3215 | (37.89) |
|  Overweight and obese, n(%) | 2151 | (51.61) | 2299 | (54.07) | 4472 | (52.70) |
| **Operation, n(%)** | 2142 | (51.39) | 388 | (9.13) | 2540 | (29.93) |
| **Stoma, n(%)** | 382 | (9.17) | 166 | (3.90) | 549 | (6.47) |
| **Pouch, n(%)** | 73 | (1.75) | 136 | (3.20) | 209 | (2.46) |
| **Fistula, n(%)** | 386 | (9.26) | 54 | (1.27) | 443 | (5.22) |
| **Biologic medication, n(%)** | 441 | (10.58) | 311 | (7.31) | 756 | (8.91) |
| **IBD medications, n(%)** | 567 | (13.60) | 1063 | (25.00) | 1640 | (19.33) |
| **Mental health conditions, n(%)** | 1083 | (25.98) | 866 | (20.37) | 1957 | (23.06) |
| **Physical health conditions, n(%)** | 1551 | (37.21) | 1671 | (39.30) | 3248 | (38.27) |
| **Pregnant, n(%)** | 37 | (0.89) | 26 | (0.61) | 63 | (0.74) |
| **Depression (PHQ-9), n(%)** |  |  |  |  |  |  |
|  None | 1663 | (39.90) | 2062 | (48.49) | 3741 | (44.08) |
|  Mild | 1074 | (25.77) | 1047 | (24.62) | 2132 | (25.12) |
|  Moderate | 663 | (15.91) | 554 | (13.03) | 1223 | (14.41) |
|  Moderately severe | 376 | (9.02) | 275 | (6.47) | 652 | (7.68) |
|  Severe | 250 | (6.00) | 178 | (4.19) | 431 | (5.08) |
|  Missing | 142 | (3.41) | 136 | (3.20) | 307 | (3.62) |
| **Anxiety (GAD-7), n(%)** |  |  |  |  |  |  |
|  None | 2032 | (48.75) | 2301 | (54.12) | 4353 | (51.30) |
|  Mild | 1047 | (25.12) | 1040 | (24.46) | 2097 | (24.71) |
|  Moderate | 536 | (12.86) | 423 | (9.95) | 962 | (11.34) |
|  Severe | 416 | (9.98) | 351 | (8.25) | 771 | (9.09) |
|  Missing  | 137 | (3.29) | 137 | (3.22) | 303 | (3.57) |
| **EQ-5D-5L index, mean (sd)** | 0.81 | (0.21) | 0.84 | (0.18) | 0.83 | (0.20) |
| **EQ-5D-5L mobility, n(%)** |  |  |  |  |  |  |
|  1 no problems | 2658 | (63.77) | 3015 | (70.91) | 5695 | (67.11) |
|  2 slight problems | 730 | (17.51) | 615 | (14.46) | 1351 | (15.92) |
|  3 moderate problems | 462 | (11.08) | 316 | (7.43) | 783 | (9.23) |
|  4 severe problems | 159 | (3.81) | 149 | (3.50) | 310 | (3.65) |
|  5 extreme problems | 5 | (0.12) | 8 | (0.19) | 13 | (0.15) |
| **EQ-5D-5L self-care, n(%)** |  |  |  |  |  |  |
|  1 no problems | 3344 | (80.23) | 3694 | (86.88) | 7068 | (83.29) |
|  2 slight problems | 376 | (9.02) | 214 | (5.03) | 593 | (6.99) |
|  3 moderate problems | 213 | (5.11) | 139 | (3.27) | 355 | (4.18) |
|  4 severe problems | 69 | (1.66) | 44 | (1.03) | 113 | (1.33) |
|  5 extreme problems | 4 | (0.10) | 4 | (0.09) | 8 | (0.09) |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **EQ-5D-5L usual activities, n(%)** |  |  |  |  |  |  |
|  1 no problems | 2125 | (50.98) | 2509 | (59.01) | 4652 | (54.82) |
|  2 slight problems | 1050 | (25.19) | 931 | (21.90) | 1991 | (23.46) |
|  3 moderate problems | 556 | (13.34) | 480 | (11.29) | 1040 | (12.26) |
|  4 severe problems | 214 | (5.13) | 135 | (3.17) | 352 | (4.15) |
|  5 extreme problems | 59 | (1.42) | 39 | (0.92) | 99 | (1.17) |
| **EQ-5D-5L pain/discomfort, n(%)** |  |  |  |  |  |  |
|  1 no problems | 1425 | (34.19) | 1787 | (42.03) | 3218 | (37.92) |
|  2 slight problems | 1448 | (34.74) | 1440 | (33.87) | 2902 | (34.20) |
|  3 moderate problems | 866 | (20.78) | 667 | (15.69) | 1546 | (18.22) |
|  4 severe problems | 213 | (5.11) | 169 | (3.97) | 383 | (4.51) |
|  5 extreme problems | 51 | (1.22) | 30 | (0.71) | 83 | (0.98) |
| **EQ-5D-5L anxiety/depression, n(%)** |  |  |  |  |  |  |
|  1 no problems | 1898 | (45.54) | 2120 | (49.86) | 4036 | (47.56) |
|  2 slight problems | 1236 | (29.65) | 1211 | (28.48) | 2457 | (28.95) |
|  3 moderate problems | 608 | (14.59) | 579 | (13.62) | 1193 | (14.06) |
|  4 severe problems | 182 | (4.37) | 131 | (3.08) | 315 | (3.71) |
|  5 extreme problems | 76 | (1.82) | 49 | (1.15) | 125 | (1.47) |
| **EV-VAS, mean (sd)** | 64.12 | (21.50) | 67.41 | (20.86) | 65.78 | (21.24) |
| **PROMIS pain, mean (sd)** | 51.27 | (11.29) | 48.40 | (10.86) | 49.85 | (11.17) |
| **PROMIS fatigue, mean (sd)** | 54.84 | (8.82) | 52.43 | (8.96) | 53.63 | (8.96) |
| **PROMIS incontinence, mean (sd)** | 6.85 | (3.47) | 6.40 | (3.36) | 6.62 | (3.42) |
| **IBD-Control, mean(sd)** | 9.65 | (4.75) | 10.85 | (4.71) | 10.25 | (4.77) |
| **IBD-Control sympt. change, n(%)** |  |  |  |  |  |  |
|  better | 302 | (7.25) | 481 | (11.31) | 787 | (9.27) |
|  no change | 3164 | (75.91) | 3114 | (73.24) | 6307 | (74.32) |
|  worse | 624 | (14.97) | 544 | (12.79) | 1172 | (13.81) |
| **IBD-Control VAS, mean (sd)** | 6.92 | (2.39) | 7.36 | (2.44) | 7.13 | (2.43) |
| **IBD Activity, mean (sd)\*** | 9.57 | (10.44) | 1.23 | (1.47) | N/A | N/A |

\* variable is calculated differently in the two groups and mean (sd) therefore are not comparable

a **Sixty-six respondents did not provide data on IBD disease type, thus rows do not sum to 8,486**

**Additional file 3, Table S4: Demographic and lifestyle characteristics by recruitment method**

|  |  |  |  |
| --- | --- | --- | --- |
| **Characteristic** | **Invited****(n=6133)** | **Self-selection****(n=2353)** | **Total****(n=8486)** |
| **Gender, n(%)** |  |  |  |  |  |  |
|  Male | 2549 | (41.56) | 736 | (31.28) | 3285 | (38.71) |
|  Female | 3392 | (55.31) | 1496 | (63.58) | 4888 | (57.60) |
|  Prefer not to say | 0 | (0) | 2 | (0.08) | 6 | (0.07) |
|  Prefer to self-define | 4 | (0.07) | 4 | (0.17) | 13 | (0.15) |
| **Age** **(years), mean (sd)** | 51.06 | (15.22) | 46.35 | (15.46) | 49.77 | (15.43) |
| **Ethnicity, n(%)** |  |  |  |  |  |  |
|  White | 5668 | (92.42) | 2083 | (88.53) | 7751 | (91.34) |
|  Mixed | 77 | (1.26) | 41 | (1.74) | 118 | (1.39) |
|  Asian | 128 | (2.09) | 81 | (3.44) | 209 | (2.46) |
|  Black | 24 | (0.39) | 11 | (0.47) | 35 | (0.41) |
|  Other | 34 | (0.55) | 17 | (0.72) | 51 | (0.60) |
|  Prefer not to say | 16 | (0.26) | 4 | (0.17) | 20 | (0.24) |
| **Employment, n(%)** |  |  |  |  |  |  |
|  Full time | 2349 | (38.30) | 996 | (42.33) | 3345 | (39.42) |
|  Part time | 803 | (13.09) | 320 | (13.60) | 1123 | (13.23) |
|  Student | 121 | (1.97) | 84 | (3.57) | 205 | (2.42) |
|  Retired | 1534 | (25.01) | 387 | (16.45) | 1921 | (22.64) |
|  Unemployed | 175 | (2.85) | 43 | (1.83) | 218 | (2.57) |
|  Self-employed | 453 | (7.39) | 150 | (6.37) | 603 | (7.11) |
|  Homemaker | 189 | (3.08) | 73 | (3.10) | 262 | (3.09) |
|  Unemployed due to illness/disability | 316 | (5.15) | 183 | (7.78) | 499 | (5.88) |
| **Education, n(%)** |  |  |  |  |  |  |
|  No formal education | 180 | (2.93) | 39 | (1.66) | 219 | (2.58) |
|  Secondary school | 1226 | (19.99) | 383 | (16.28) | 1609 | (18.96) |
|  Sixth form | 490 | (7.99) | 178 | (7.56) | 668 | (7.87) |
|  Further education | 1697 | (27.67) | 573 | (24.35) | 2270 | (26.75) |
|  Higher education | 2328 | (37.96) | 1063 | (45.18) | 3391 | (39.96) |
| **Relationship Status, n(%)** |  |  |  |  |  |  |
|  Married/ civil partnership | 3425 | (55.85) | 1082 | (45.98) | 4507 | (53.11) |
|  Living with partner | 884 | (14.41) | 388 | (16.49) | 1272 | (14.99) |
|  Widowed | 165 | (2.69) | 37 | (1.57) | 202 | (2.38) |
|  Divorced/separated | 330 | (5.38) | 129 | (5.48) | 459 | (5.41) |
|  Single | 858 | (13.99) | 435 | (18.49) | 1293 | (15.24) |
| With partner, not living together | 259 | (4.22) | 165 | (7.01) | 424 | (5.00) |
| **Smoker, n(%)** |  |  |  |  |  |  |
|  Never | 2944 | (48.00) | 1221 | (51.89) | 4165 | (49.08) |
|  Ex | 2588 | (42.20) | 876 | (37.23) | 3464 | (40.82) |
|  Current | 393 | (6.41) | 136 | (5.78) | 529 | (6.23) |
| **Alcohol** **(units/week) – mean (sd)** | 0.67 | (0.63) | 0.60 | (0.62) | 0.66 | (0.63) |

**Additional file 3, Table S5: Clinical characteristics by recruitment method**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Characteristic** | **Invited****(n=6133)** | **Self-selection****(n=2353)** | **Total****(n=8486)** | **P-value** |
| **BMI (kg/m2), mean (SD)** | 26.82 | (5.76) | 26.91 | (6.21) | 26.85 | (5.89) | 0.55 |
| **BMI categories (kg/m2)** |  |  |  |  |  |  | 0.25 |
|  Underweight, n (%) | 128 | (2.09) | 67 | (2.85) | 195 | (2.30) |  |
|  Healthy weight, n (%) | 2325 | (37.91) | 890 | (37.82) | 3215 | (37.89) |  |
|  Overweight & obese, n (%) | 3257 | (53.11) | 1215 | (51.64) | 4472 | (52.70) |  |
| **Operation, n (%)** | 1870 | (30.49) | 670 | (28.47) | 2540 | (29.93) | 0.89 |
| **Stoma, n (%)** | 391 | (6.38) | 158 | (6.71) | 549 | (6.47) | 0.57 |
| **Pouch, n (%)** | 147 | (2.40) | 62 | (2.63) | 209 | (2.46) | 0.54 |
| **Fistula, n(%)** | 294 | (4.79) | 149 | (6.33) | 443 | (5.22) | 0.0040 |
| **Biologic medications, n (%)** | 509 | (8.30) | 247 | (10.50) | 756 | (8.91) | 0.0052 |
| **IBD medications, n (%)** | 1219 | (19.88) | 421 | (17.89) | 1640 | (19.33) | 0.0450 |
| **Mental health conditions, n (%)** | 1282 | (20.90) | 675 | (28.69) | 1957 | (23.06) | <0.0001 |
| **Physical health conditions, n (%)** | 2414 | (39.36) | 834 | (35.44) | 3248 | (38.27) | 0.0009 |
| **Pregnant, n (%)** | 46 | (0.75) | 17 | (0.72) | 63 | (0.74) | 0.93 |
| **Depression (PHQ-9), n (%)** |  |  |  |  |  |  | <0.0001 |
|  None | 2974 | (48.49) | 767 | (32.60) | 3741 | (44.08) |  |
|  Mild | 1482 | (24.16) | 650 | (27.62) | 2132 | (25.12) |  |
|  Moderate | 834 | (13.60) | 389 | (16.53) | 1223 | (14.41) |  |
|  Moderately severe | 410 | (6.69) | 242 | (10.28) | 652 | (7.68) |  |
|  Severe | 244 | (3.98) | 187 | (7.95) | 431 | (5.08) |  |
| **Anxiety (GAD-7), n (%)** |  |  |  |  |  |  | <0.0001 |
|  None | 3393 | (55.32) | 960 | (40.80) | 4353 | (51.30) |  |
|  Mild | 1456 | (23.74) | 641 | (27.24) | 2097 | (24.71) |  |
|  Moderate | 629 | (10.26) | 333 | (14.15) | 962 | (11.34) |  |
|  Severe | 463 | (7.55) | 308 | (13.09) | 771 | (9.09) |  |
| **EQ-5D-5L index, mean (SD)** | 0.84 | (0.18) | 0.78 | (0.22) | 0.83 | (0.20) |  |
|  **Mobility, n (%)** |  |  |  |  |  |  | <0.0001 |
|  1 no problems | 4271 | (69.64) | 1424 | (60.52) | 5695 | (67.11) |  |
|  2 slight problems | 925 | (15.08) | 426 | (18.10) | 1351 | (15.92) |  |
|  3 moderate problems | 515 | (8.40) | 268 | (11.39) | 783 | (9.23) |  |
|  4 severe problems | 200 | (3.26) | 110 | (4.67) | 310 | (3.65) |  |
|  5 extreme problems | 9 | (0.15) | 4 | (0.17) | 13 | (0.15) |  |
|  **Self-care, n (%)** |  |  |  |  |  |  | <0.0001 |
|  1 no problems | 5245 | (85.52) | 1823 | (77.48) | 7068 | (83.29) |  |
|  2 slight problems | 386 | (6.29) | 207 | (8.80) | 593 | (6.99) |  |
|  3 moderate problems | 210 | (3.42) | 145 | (6.16) | 355 | (4.18) |  |
|  4 severe problems | 66 | (1.08) | 47 | (2.00) | 113 | (1.33) |  |
|  5 extreme problems | 3 | (0.05) | 5 | (0.21) | 8 | (0.09) |  |
|  **Usual activities, n(%)** |  |  |  |  |  |  | <0.0001 |
|  1 no problems | 3622 | (59.06) | 1030 | (43.77) | 4652 | (54.82) |  |
|  2 slight problems | 1354 | (22.08) | 637 | (27.07) | 1991 | (23.46) |  |
|  3 moderate problems | 656 | (10.70) | 384 | (16.32) | 1040 | (12.26) |  |
|  4 severe problems | 225 | (3.67) | 127 | (5.40) | 352 | (4.15) |  |
|  5 extreme problems | 51 | (0.83) | 48 | (2.04) | 99 | (1.17) |  |
|  **Pain/discomfort, n(%)** |  |  |  |  |  |  | <0.0001 |
|  1 no problems | 2552 | (41.61) | 666 | (28.30) | 3218 | (37.92) |  |
|  2 slight problems | 2058 | (33.56) | 844 | (35.87) | 2902 | (34.20) |  |
|  3 moderate problems | 1001 | (16.32) | 545 | (23.16) | 1546 | (18.22) |  |
|  4 severe problems | 243 | (3.96) | 140 | (5.95) | 383 | (4.51) |  |
|  5 extreme problems | 52 | (0.85) | 31 | (1.32) | 83 | (0.98) |  |
|  **Anxiety/depression, n(%)** |  |  |  |  |  |  | <0.0001 |
|  1 no problems | 3143 | (51.25) | 893 | (37.95) | 4036 | (47.56) |  |
|  2 slight problems | 1728 | (28.18) | 729 | (30.98) | 2457 | (28.95) |  |
|  3 moderate problems | 783 | (12.77) | 410 | (17.42) | 1193 | (14.06) |  |
|  4 severe problems | 179 | (2.92) | 136 | (5.78) | 315 | (3.71) |  |
|  5 extreme problems | 70 | (1.14) | 55 | (2.34) | 125 | (1.47) |  |
| **EQ-VAS score, mean (SD)** | 67.84 | (20.63) | 60.31 | (21.85) | 65.78 | (21.24) | <0.0001 |
| **PROMIS pain intensity, mean (SD)** | 48.87 | (11.04) | 52.45 | (11.08) | 49.85 | (11.17) | <0.0001 |
| **PROMIS fatigue, mean (SD)** | 52.69 | (8.90) | 56.09 | (8.64) | 53.63 | (8.96) | <0.0001 |
| **PROMIS incontinence, mean (SD)** | 6.45 | (3.31) | 7.06 | (3.67) | 6.62 | (3.42) | <0.0001 |
| **IBD Control, mean (SD)** | 10.85 | (4.57) | 8.66 | (4.90) | 10.25 | (4.77) | <0.0001 |
| **IBD Control - symptom change, n (%)** |  |  |  |  |  |  | <0.0001 |
|  Better | 552 | (9.00) | 235 | (9.99) | 787 | (9.27) |  |
|  No change | 4712 | (76.83) | 1595 | (67.79) | 6307 | (74.32) |  |
|  Worse | 729 | (11.89) | 443 | (18.83) | 1172 | (13.81) |  |
| **IBD Control - VAS, mean (SD)** | 7.37 | (2.37) | 6.51 | (2.48) | 7.13 | (2.43) | <0.0001 |
| **IBD Activity** |  |  |  |  |  |  |  |
|  Crohn's Disease, mean (SD) | 8.98 | (9.42) | 11.01 | (12.46) | 9.55 | (10.41) | <0.0001 |
|  Ulcerative Colitis, mean (SD) | 1.11 | (1.40) | 1.57 | (1.62) | 1.23 | (1.47) | <0.0001 |

**Additional file 3, Table S6: demographic and lifestyle characteristics by symptom**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Characteristic** | **Pain****(n=1769)** | **Fatigue****(n=2036)** | **Incontinence****(n=4562)** | **Total****(N=8486)** |
| **Gender, n(%)** |  |  |  |  |  |  |  |  |
|  Male | 514 | (29.06) | 522 | (25.64) | 1687 | (36.98) | 3285 | (38.71) |
|  Female | 1204 | (68.06) | 1458 | (71.61) | 2793 | (61.22) | 4888 | (57.60) |
|  Prefer not to say | 2 | (0.11) | 2 | (0.10) | 3 | (0.07) | 6 | (0.07) |
|  Prefer to self-define | 5 | (0.28) | 4 | (0.20) | 9 | (0.20) | 13 | (0.15) |
| **Age** **(years), mean (sd)** | 47.18 | (14.62) | 46.04 | (14.29) | 51.10 | (15.10) | 49.77 | (15.43) |
| **Ethnicity, n(%)** |  |  |  |  |  |  |  |  |
|  White | 1612 | (91.12) | 1857 | (91.21) | 4261 | (93.40) | 7751 | (91.34) |
|  Mixed | 31 | (1.75) | 45 | (2.21) | 63 | (1.38) | 118 | (1.39) |
|  Asian | 50 | (2.83) | 53 | (2.60) | 105 | (2.30) | 209 | (2.46) |
|  Black | 10 | (0.57) | 10 | (0.49) | 21 | (0.46) | 35 | (0.41) |
|  Other | 11 | (0.62) | 12 | (0.59) | 24 | (0.53) | 51 | (0.60) |
|  Prefer not to say | 7 | (0.40) | 6 | (0.29) | 14 | (0.31) | 20 | (0.24) |
| **Employment, n(%)** |  |  |  |  |  |  |  |  |
|  Full time | 634 | (35.84) | 710 | (34.87) | 1757 | (38.51) | 3345 | (39.42) |
|  Part time | 229 | (12.95) | 320 | (15.72) | 616 | (13.50) | 1123 | (13.23) |
|  Student | 38 | (2.15) | 57 | (2.80) | 83 | (1.82) | 205 | (2.42) |
|  Retired | 253 | (14.30) | 250 | (12.28) | 1068 | (23.41) | 1921 | (22.64) |
|  Unemployed | 77 | (4.35) | 83 | (4.08) | 137 | (3.00) | 218 | (2.57) |
|  Self-employed | 122 | (6.90) | 132 | (6.48) | 308 | (6.75) | 603 | (7.11) |
|  Homemaker | 65 | (3.67) | 92 | (4.52) | 153 | (3.35) | 262 | (3.09) |
|  Unemployed due to illness/disability | 298 | (16.85) | 336 | (16.50) | 363 | (7.96) | 499 | (5.88) |
| **Education, n(%)** |  |  |  |  |  |  |  |  |
|  No formal education | 61 | (3.45) | 63 | (3.09) | 144 | (3.16) | 219 | (2.58) |
|  Secondary school | 429 | (24.25) | 449 | (22.05) | 1029 | (22.56) | 1609 | (18.96) |
|  Sixth form | 153 | (8.65) | 176 | (8.64) | 333 | (7.30) | 668 | (7.87) |
|  Further education | 570 | (32.22) | 626 | (30.75) | 1331 | (29.18) | 2270 | (26.75) |
|  Higher education | 496 | (28.04) | 660 | (32.42) | 1633 | (35.80) | 3391 | (39.96) |
| **Relationship Status, n(%)** |  |  |  |  |  |  |  |  |
|  Married/ civil partnership | 797 | (45.05) | 896 | (44.01) | 2492 | (54.63) | 4507 | (53.11) |
|  Living with partner | 286 | (16.17) | 334 | (16.40) | 673 | (14.75) | 1272 | (14.99) |
|  Widowed | 45 | (2.54) | 49 | (2.41) | 123 | (2.70) | 202 | (2.38) |
|  Divorced/separated | 127 | (7.18) | 153 | (7.51) | 295 | (6.47) | 459 | (5.41) |
|  Single | 349 | (19.73) | 406 | (19.94) | 675 | (14.80) | 1293 | (15.24) |
| With partner, not living together | 107 | (6.05) | 132 | (6.48) | 218 | (4.78) | 424 | (5.00) |
| **Smoker, n(%)** |  |  |  |  |  |  |  |  |
|  Never | 755 | (42.68) | 926 | (45.48) | 2073 | (45.44) | 4507 | (49.08) |
|  Ex | 772 | (43.64) | 839 | (41.21) | 2043 | (44.78) | 3464 | (40.82) |
|  Current | 186 | (10.51) | 208 | (10.22) | 358 | (7.85) | 529 | (6.23) |
| **Alcohol** **(units/week) – mean (sd)** | 0.47 | (0.58) | 0.45 | (0.57) | 0.63 | (0.63) | 0.66 | (0.63) |

**Additional file 3, Table S7: clinical characteristics and PROMIS symptom scores by symptom**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Characteristic** | **Pain****(n=1769)** | **Fatigue****(n=2036)** | **Incontinence****(n=4562)** | **Total****(n=8486)** |
| **BMI (kg/m2)**, mean(sd) | 27.95 | (6.69) | 28.20 | (6.90) | 27.50 | (6.18) | 26.85 | (5.89) |
| Underweight, n(%) | 59 | (3.34) | 63 | (3.09) | 98 | (2.15) | 195 | (2.30) |
| Healthy weight, n(%) | 548 | (30.98) | 645 | (31.68) | 1588 | (34.81) | 3215 | (37.89) |
| Overweight & obese, n(%) | 1046 | (59.13) | 1209 | (59.38) | 2636 | (57.78) | 4472 | (52.70) |
| **Operation**, n(%) | 633 | (35.78) | 735 | (36.10) | 1369 | (30.01) | 2540 | (29.93) |
| **Stoma**, n(%) | 130 | (7.35) | 195 | (9.58) | 34 | (0.75) | 549 | (6.47) |
| **Pouch**, n(%) | 54 | (3.05) | 57 | (2.80) | 113 | (2.48) | 209 | (2.46) |
| **Fistula**, n(%) | 155 | (8.76) | 152 | (7.47) | 279 | (6.12) | 443 | (5.22) |
| **Biological medications**, n(%) | 182 | (10.29) | 221 | (10.85) | 437 | (9.58) | 756 | (8.91) |
| **IBD medications**, n(%) | 351 | (19.84) | 385 | (18.91) | 971 | (21.28) | 1640 | (19.33) |
| **Mental health conditions**, n(%) | 695 | (39.29) | 887 | (43.57) | 1232 | (27.01) | 1957 | (23.06) |
| **Physical health conditions**, n(%) | 790 | (44.66) | 906 | (44.50) | 1924 | (42.17) | 3248 | (38.27) |
| **Pregnant**, n(%) | 9 | (0.51) | 9 | (0.44) | 24 | (0.53) | 63 | (0.74) |
| **Depression (PHQ-9)**, n(%) |  |  |  |  |  |  |  |  |
| None | 222 | (12.55) | 136 | (6.68) | 1583 | (34.70) | 3741 | (44.08) |
| Mild | 452 | (25.55) | 510 | (25.05) | 1283 | (28.12) | 2132 | (25.12) |
| Moderate | 437 | (24.70) | 547 | (26.87) | 816 | (17.89) | 1223 | (14.41) |
| Moderately severe | 321 | (18.15) | 437 | (21.46) | 467 | (10.24) | 652 | (7.68) |
| Severe | 294 | (16.62) | 350 | (17.19) | 348 | (7.63) | 431 | (5.08) |
| Missing | 43 | (2.43) | 56 | (2.75) | 65 | (1.42) | 307 | (3.62) |
| **Anxiety (GAD-7)**, n(%) |  |  |  |  |  |  |  |  |
| None | 426 | (24.08) | 419 | (20.58) | 2020 | (44.28) | 4353 | (51.30) |
| Mild | 497 | (28.09) | 594 | (29.17) | 1245 | (27.29) | 2097 | (24.71) |
| Moderate | 394 | (22.27) | 460 | (22.59) | 649 | (14.23) | 962 | (11.34) |
| Severe | 407 | (23.01) | 510 | (25.05) | 572 | (12.54) | 771 | (9.09) |
| Missing | 45 | (2.54) | 53 | (2.60) | 76 | (1.67) | 303 | (3.57) |
| **EQ-5D-5L index**, mean(sd) | 0.64 | (0.26) | 0.65 | (0.25) | 0.79 | (0.21) | 0.83 | (0.20) |
| **EQ-5D-5L mobility**, n(%) |  |  |  |  |  |  |  |  |
| 1 no problems | 676 | (38.21) | 808 | (39.69) | 2822 | (61.86) | 5695 | (67.11) |
| 2 slight problems | 443 | (25.04) | 502 | (24.66) | 862 | (18.90) | 1351 | (15.92) |
| 3 moderate problems | 399 | (22.56) | 450 | (22.10) | 546 | (11.97) | 783 | (9.23) |
| 4 severe problems | 189 | (10.68) | 206 | (10.12) | 236 | (5.17) | 310 | (3.65) |
| 5 extreme problems | 6 | (0.34) | 5 | (0.25) | 10 | (0.22) | 13 | (0.15) |
| **EQ-5D-5L self-care**, n(%) |  |  |  |  |  |  |  |  |
| 1 no problems | 1103 | (62.35) | 1251 | (61.44) | 3697 | (81.04) | 7068 | (83.29) |
| 2 slight problems | 288 | (16.28) | 370 | (18.17) | 406 | (8.90) | 593 | (6.99) |
| 3 moderate problems | 227 | (12.83) | 249 | (12.23) | 269 | (5.90) | 355 | (4.18) |
| 4 severe problems | 84 | (4.75) | 90 | (4.42) | 89 | (1.95) | 113 | (1.33) |
| 5 extreme problems | 6 | (0.34) | 6 | (0.29) | 6 | (0.13) | 8 | (0.09) |
| **EQ-5D-5L activities**, n(%) |  |  |  |  |  |  |  |  |
| 1 no problems | 375 | (21.20) | 393 | (19.30) | 2128 | (46.65) | 4652 | (54.82) |
| 2 slight problems | 539 | (30.47) | 628 | (30.84) | 1252 | (27.44) | 1991 | (23.46) |
| 3 moderate problems | 499 | (28.21) | 597 | (29.32) | 747 | (16.37) | 1040 | (12.26) |
| 4 severe problems | 221 | (12.49) | 265 | (13.02) | 266 | (5.83) | 352 | (4.15) |
| 5 extreme problems | 72 | (4.07) | 80 | (3.93) | 72 | (1.58) | 99 | (1.17) |

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **EQ-5D-5L pain/discomfort**, n(%) |  |  |  |  |  |  |  |  |
| 1 no problems | 64 | (3.62) | 274 | (13.46) | 1259 | (27.60) | 3218 | (37.92) |
| 2 slight problems | 399 | (22.56) | 600 | (29.47) | 1729 | (37.90) | 2902 | (34.20) |
| 3 moderate problems | 869 | (49.12) | 754 | (37.03) | 1109 | (24.31) | 1546 | (18.22) |
| 4 severe problems | 303 | (17.13) | 272 | (13.36) | 305 | (6.69) | 383 | (4.51) |
| 5 extreme problems | 71 | (4.01) | 63 | (3.09) | 62 | (1.36) | 83 | (0.98) |
| **EQ-5D-5L anxiety/depression**, n(%) |  |  |  |  |  |  |  |  |
| 1 no problems | 418 | (23.63) | 420 | (20.63) | 1899 | (41.63) | 4036 | (47.56) |
| 2 slight problems | 549 | (31.03) | 621 | (30.50) | 1460 | (32.00) | 2457 | (28.95) |
| 3 moderate problems | 481 | (27.19) | 604 | (29.67) | 778 | (17.05) | 1193 | (14.06) |
| 4 severe problems | 170 | (9.61) | 212 | (10.41) | 224 | (4.91) | 315 | (3.71) |
| 5 extreme problems | 87 | (4.92) | 105 | (5.16) | 98 | (2.15) | 125 | (1.47) |
| **EQ-VAS score**, mean(sd) | 47.19 | (20.37) | 48.11 | (19.84) | 60.50 | (21.42) | 65.78 | (21.24) |
| **PROMIS pain intensity**, mean(sd) | 65.42 | (4.08) | 58.32 | (10.34) | 53.09 | (10.88) | 49.85 | (11.17) |
| **PROMIS fatigue**, mean(sd) | 61.13 | (7.10) | 64.71 | (4.04) | 55.91 | (8.36) | 53.63 | (8.96) |
| **PROMIS incontinence**, mean(sd) | 9.20 | (4.20) | 8.65 | (4.14) | 8.39 | (3.44) | 6.62 | (3.42) |
| **IBD-control**, mean(sd) | 5.19 | (3.75) | 6.20 | (4.04) | 8.62 | (4.68) | 10.25 | (4.77) |
| **IBD-Control symptom change**, n(%) |  |  |  |  |  |  |  |  |
| Better | 142 | (8.03) | 169 | (8.30) | 474 | (10.39) | 787 | (9.27) |
| No change | 1095 | (61.90) | 1361 | (66.85) | 3230 | (70.80) | 6307 | (74.32) |
| Worse | 520 | (29.40) | 481 | (23.62) | 849 | (18.61) | 1172 | (13.81) |
| **IBD-control VAS**, mean(sd) | 5.18 | (2.29) | 5.72 | (2.43) | 6.34 | (2.40) | 7.13 | (2.43) |
| **IBD activity CD**, mean(sd) | 17.48 | (13.47) | 15.01 | (13.24) | 12.36 | (11.35) | 9.57 | (10.44) |
| **IBD activity UC**, mean(sd) | 2.34 | (1.71) | 2.05 | (1.68) | 1.79 | (1.60) | 1.23 | (1.47) |