**\$1.** Complete data set for prospective cohort at 0 months and 4 months, and retrospective cohort.

|   |                 | Prospective 0 months | Prospective<br>4 months | Retrospective |
|---|-----------------|----------------------|-------------------------|---------------|
| 1. Do you believe that: (a) your IBD has been well controlled in the past two weeks?  | Yes             | 21                   | 25                      | 29            |
|   | No              | 12                   | 8                       | 4             |
|   | Not sure        | 2                    | 2                       | 2             |
| 4.5   | Yes             | 26                   | 25                      | 25            |
| Do you believe that: (b) your current treatment is useful in controlling your IBD?  | No              | 2                    | 2                       | 2             |
|   | Not sure        | 6                    | 6                       | 4             |
|   | Not taking meds | 1                    | 2                       | 4             |
| 2. Over the past 2 weeks, have your bowel symptoms been getting worse, getting better or not changed?   | Better          | 10                   | 6                       | 5             |
|   | Worse           | 3                    | 7                       | 2             |
|   | No change       | 22                   | 22                      | 28            |
| 3. In the past 2 weeks, did you: (a) miss any planned activities because of IBD (eg attending school/college, going to work or a social event)? | Yes             | 8                    | 9                       | 7             |
|   | No              | 27                   | 25                      | 28            |
|   | Not sure        | 0                    | 1                       | 0             |
| 3. In the past 2 weeks, did you:  | Yes             | 10                   | 10                      | 14            |
| (b) wake up at night because of   | No              | 24                   | 25                      | 20            |
| symptoms of IBD?  | Not sure        | 1                    | 0                       | 1             |
| 3. In the past 2 weeks, did you:<br>(c) suffer from significant pain or<br>discomfort?  | Yes             | 10                   | 12                      | 13            |
|   | No              | 25                   | 23                      | 20            |
|   | Not sure        | 0                    | 0                       | 1             |
| 3. In the past 2 weeks, did you:<br>(d) often feel lacking in energy<br>(fatigued)?   | Yes             | 21                   | 19                      | 18            |
|   | No              | 13                   | 12                      | 15            |
|   | Not sure        | 1                    | 4                       | 2             |
| 3. In the past 2 weeks, did you:<br>(e) feel anxious or depressed<br>because of your IBD?   | Yes             | 11                   | 13                      | 11            |
|   | No              | 23                   | 21                      | 22            |
|   | Not sure        | 1                    | 1                       | 2             |
| 3. In the past 2 weeks, did you: (f) think you needed a change to your treatment?   | Yes             | 6                    | 7                       | 5             |
|   | No              | 23                   | 24                      | 26            |
|   | Not sure        | 6                    | 4                       | 4             |
| 4. At your next clinic visit, would you like to discuss: (a) alternative types of drug for controlling IBD?                                     | Yes             | 15                   | 12                      | 9             |
|   | No              | 15                   | 17                      | 21            |
|   | Not sure        | 5                    | 6                       | 5             |
| 4. At your next clinic visit, would you like to discuss: (b) ways to adjust your own treatment?   | Yes             | 12                   | 14                      | 9             |
|   | No              | 19                   | 15                      | 19            |
|   | Not sure        | 4                    | 6                       | 7             |
| 4. At your next clinic visit, would you like to discuss: (c) side effects or difficulties with using your medicines?                            | Yes             | 8                    | 14                      | 6             |
|   | No              | 25                   | 18                      | 27            |
|   | Not sure        | 2                    | 3                       | 2             |

| 4. At your next clinic visit, would you like to discuss: (d) new symptoms that have developed since your last visit?                   | Yes               | 9  | 10 | 7  |
|--|-------------------|----|----|----|
|  | No                | 24 | 21 | 25 |
|  | Not sure          | 2  | 4  | 3  |
| 5. How would you rate the<br>OVERALL control of your IBD in<br>the past two weeks?   | 1                 | 0  | 0  | 0  |
|  | 2                 | 2  | 0  | 0  |
|  | 3                 | 0  | 3  | 0  |
|  | 4                 | 6  | 2  | 3  |
|  | 5                 | 0  | 4  | 3  |
|  | 6                 | 5  | 3  | 2  |
|  | 7                 | 6  | 5  | 7  |
|  | 8                 | 8  | 6  | 5  |
|  | 9                 | 4  | 9  | 6  |
|  | 10                | 4  | 3  | 9  |
| The non-face-to-face service (eg IBD helpline, Patients Know Best) has (a) had a positive impact on my IBD.                            | Disagree strongly | -  | -  | 0  |
|  | Disagree          | -  | -  | 10 |
|  | Agree             | -  | -  | 12 |
|  | Agree strongly    | -  | -  | 12 |
|  | N/A               | -  | -  | 1  |
| The non-face-to-face service (eg IBD helpline, Patients Know Best) has (b) helped me to feel more confident in managing my own health. | Disagree strongly | -  | -  | 0  |
|  | Disagree          | -  | -  | 7  |
|  | Agree             | -  | -  | 15 |
|  | Agree strongly    | -  | -  | 12 |
|  | N/A               | -  | -  | 1  |
| The non-face-to-face service (eg<br>IBD helpline, Patients Know<br>Best) has (c) improved my<br>quality of life.                       | Disagree strongly | -  | -  | 1  |
|  | Disagree          | -  | -  | 10 |
|  | Agree             | -  | -  | 12 |
|  | Agree strongly    | -  | -  | 8  |
|  | N/A               | -  | -  | 4  |

IBD = inflammatory bowel disease; often = more than half of the time.