

Supplementary Material 1. Questionnaire

Background

1. In which country do you live?
 - a. France
 - b. Germany
 - c. Italy
 - d. Spain
 - e. Sweden
 - f. UK
 - g. Canada
 - h. Finland

2. Are you male or female?
 - a. Male
 - b. Female

3. What was your year of birth?
[select]

4. What is your highest level of education?
 - a. Primary education
 - b. Secondary education
 - c. University education

5. What is your main occupation today?
 - a. Working (employee)
 - b. Working (self-employed)
 - c. Studying
 - d. Unemployed
 - e. Long term sick leave because of IBD
 - f. Long term sick leave for other reasons
 - g. Retired early due to IBD
 - h. Retired early for other reasons
 - i. Retired (because of age)
 - j. None of the above, but fulfilling family role as parent or partner
 - k. Other

6. On average how often did you use the internet in the last 3 months?
 - a. Every day or almost every day
 - b. At least once a week (but not every day)
 - c. At least once a month (but not every week)
 - d. Less than once a month

7. How did you receive the invitation to answer the questionnaire?
 - a. Through information/banner on webpage
 - b. Via email
 - c. Via letter

- d. Via Facebook
- e. Via Twitter
- f. Through recommendation from friend/acquaintance
- g. Other way

8. Are you currently a smoker?

- a. Yes
- b. No, have been before but quit due to IBD
- c. No, have been before but quit due to other reasons
- d. No, and have never been

About your IBD

9. Has a doctor diagnosed you with any of the following forms of IBD (Inflammatory Bowel Disease)? If your diagnosis has changed, please indicate current diagnosis

- a. Crohn's disease
- b. Ulcerative colitis
- c. Indeterminate colitis
- d. Other colitis
- e. No, I have not been diagnosed with any of these
- f. Since you are not diagnosed with IBD you are not part of the target group for this survey.

Thank you for your time.

10. Where is your Crohn's or Colitis located?

- a. Small bowel
- b. Where small bowel and large bowel meet (ileocaecal)
- c. Large bowel
- d. Rectum
- e. Other
- f. Don't know

11. Do you believe that your IBD has been well controlled in the past two weeks?

- a. Yes
- b. No
- c. Not sure

12. Do you believe that your current treatment is useful in controlling your IBD?

- a. Yes
- b. No
- c. Not sure
- d. I'm currently not taking any treatment

13. In the past two weeks, did you: Please answer yes or no

- a. Miss any planned activities because of IBD? (e.g. attending school/college, going to work or a social event)
- b. Wake up at night because of symptoms of IBD?
- c. Suffer from significant pain or discomfort?
- d. Often feel lacking in energy (fatigued)? (by 'often', we mean more than half the time)
- e. Feel anxious or depressed because of your IBD?

14. Think you needed a change to your treatment?

- a. Yes
- b. No
- c. Not sure

15. Are you currently a member of an IBD patient association?

- a. Yes
- b. No

16. Have you had abdominal surgery as a result of your IBD condition?

- a. Yes
- b. No

17. Have you ever had a stoma ("bag")

- a. Yes, currently
- b. Yes, previously but not currently
- c. No

18. In what year did you experience your first symptoms that you now recognise as related to IBD? (If you are not sure, please give your best estimate)

[select]

19. In what year were you diagnosed with IBD? (If you are not sure, please give your best estimate)

[select]

20. From the time of first seeking medical care for symptoms that you now recognise as related to IBD, how long did it take to get a confirmed IBD diagnosis?

- a. Less than 1 month
- b. 2–3 months
- c. 4–6 months
- d. 7–12 months
- e. 13–24 months
- f. 25–48 months
- g. More than 48 months

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

- a. None
- b. 1
- c. 2
- d. 3
- e. 4
- f. 5
- g. More than five
- h. Don't know/Can't remember

22. How would you rate your IBD activity at the time you were diagnosed with IBD?

- a. Minimally active (symptoms not interfering with main occupation or recreation)
- b. Mildly active (some interference with main occupation or recreation)
- c. Moderately active (extensive interference with main occupation or recreation)
- d. Severely active (admitted to hospital)

23. Thinking about the last 3 months, how would you rate your IBD activity?

- a. Remission (no symptoms, normal bowel pattern)
- b. Minimally active (symptoms not interfering with main occupation or recreation)
- c. Mildly active (some interference with main occupation or recreation)
- d. Moderately active (extensive interference with main occupation or recreation)
- e. Severely active (admitted to hospital)

24. How many flare-ups have you experienced in the last 12 months? If you are not sure, please give your best estimate.

- a. None
- b. 1
- c. 2
- d. 3
- e. 4
- f. 5
- g. More than 5
- h. Continuous active symptoms during the last 12 months
- i. Don't know

25. How many times have you been admitted to hospital because of IBD-related symptoms in the last 12 months? If you are not sure, please give your best estimate.

- a. None
- b. 1
- c. 2
- d. 3
- e. 4
- f. 5
- g. More than 5
- h. Don't know

26. How many days in the last 12 months have you...

- a. Been absent from school or college due to IBD-related symptoms?
- b. Been absent from work due to IBD-related symptoms?
- c. Been unable to do normal activities, due to IBD-related symptoms?
 - i. None
 - ii. 1 day
 - iii. 2 days
 - iv. 3 days
 - v. 4 days
 - vi. 5 days
 - vii. 6–10 days
 - viii. 11–15 days
 - ix. 16–20 days
 - x. 20–25 days
 - xi. More than 25 days

About your IBD medication

27. Have you taken steroid tablets for IBD at any time in the last 24 months?

- a. Yes
- b. No
- c. Not sure

28. In the last 24 months, what is the longest continuous stretch of time that you have been taking steroid tablets for your IBD?

- a. Less than 3 months
- b. 4-6 months
- c. 7-12 months
- d. More than 12 months
- e. Not sure

29. Are you currently taking/receiving: Please answer yes or no

- a. Steroid tablets for IBD?
- b. Steroid-sparing medication? (e.g., azathioprine, 6-mercaptopurine, methotrexate)
- c. A prescribed probiotic medicine?
- d. A prescribed anti-depressant medication?
- e. A prescribed medication for pain-relief?
- f. Infusions or injections of biologic medication (e.g., infliximab, adalimumab)

30. Are you taking any probiotic or herbal medicines which have not been prescribed or using any form of complementary therapy?

- a. Yes
- b. No
- c. Not sure

About your IBD care

31. Did the specialist who looked after you for the first three months after the diagnosis was made discuss with you the following topics?

- a. Characteristics of the disease (progressive, fluctuating, etc)
- b. Available treatment and their role
- c. Treatment goals
- d. Benefit/risk of the treatment options
- e. Calprotectin to measure disease activity
- f. How IBD might affect your education or employment
- g. Importance of smoking cessation
 - i. Yes
 - ii. No
 - iii. Don't remember

32. When, if ever, were the following tools offered to you after your IBD diagnosis was made?

- a. Consultation with a specialist nurse
- b. Leaflets
- c. Group education
- d. Information about relevant patient organisations
- e. Smoking cessation programme
 - i. Offered within 3 months
 - ii. Offered within 4-12 months
 - iii. Offered after more than 12 months
 - iv. Never offered
 - v. Don't know/Can't remember

33. What has been discussed with you as the aim(s) of your treatment? Please tick all that apply.

- a. Relief of symptoms
- b. Remission
- c. Healing the mucosa
- d. Getting back to work or education
- e. Other
- f. Aims of treatment have never been discussed

34. Who do you normally consult about your IBD?

- a. GP/Family doctor
- b. Gastroenterologist
- c. General surgeon
- d. Colorectal surgeon
- e. Other hospital doctor
- f. Specialist nurse

35. Where are they based?

- a. Local surgery/healthcare clinic
- b. General hospital
- c. University hospital
- d. Private clinic
- e. Private Hospital

36. Do you have a regular IBD review appointment whether or not your IBD is active at the time?

- a. No
- b. Yes, about every 3 months
- c. Yes, about every 6 months
- d. Yes, about once a year
- e. Yes, but more seldom than once a year

37. How was your last IBD review carried out?

- a. Face to face appointment
- b. Via telephone
- c. Via email
- d. Via postal questionnaire

38. How long did your last IBD review consultation last?

- a. Around 5 minutes
- b. Around 10 minutes
- c. Around 15 minutes
- d. Around 20 minutes
- e. Around 25 minutes
- f. Around 30 minutes
- g. More than 30 minutes

39. Did you consider this was enough time to review your IBD satisfactorily?

- a. Yes
- b. No

40. Who decided you should not have a regular review?
- Hospital clinical staff (gastroenterologist, surgeon, nurse)
 - GP
 - Myself, in discussion with doctor
 - Myself, on my own
41. What is your opinion about not having a regular IBD review?
- It is not needed since my IBD is not active
 - It is not needed. My IBD is active but I seek help when I want it
 - I would like one if available
42. Who do you normally get your specialist advice from if you have a flare up?
- GP/Family doctor
 - Gastroenterologist
 - General surgeon
 - Colorectal surgeon
 - Other hospital doctor
 - Specialist nurse
 - I have no access to specialist advice in case of a flare-up
43. Where is the person based from whom you normally get your specialist advice if you have a flare-up?
- Local surgery/healthcare clinic
 - General hospital
 - University hospital
 - Private clinic
 - Private Hospital
44. How do you usually get your specialist advice if you have a flare-up?
- Telephone
 - Hospital or clinic visit
 - Email
45. How quickly can you usually access specialist advice when a flare-up occurs?
- Same day
 - Within 1-3 days
 - Within 4-7 days
 - After more than 7 days
46. In what year did you last have an overnight stay in hospital in relation to your IBD?
- Have never had overnight stay in hospital due to IBD
 - Year:
47. On that occasion, were you on a specialist gastroenterology ward?
- Yes
 - No
 - Don't know

48. On that occasion, did you think that the number of toilets was adequate for a patient with IBD?

- a. Yes
- b. No
- c. Don't know

49. Do you currently have access to any of the following healthcare professionals for the treatment of your IBD?

- a. Specialist nurse
- b. Dietician
- c. Psychologist
- d. Colorectal surgeon
- e. Rheumatologist
- f. Dermatologist
- g. Counsellor
- h. Social worker
- i. Yes
- j. No, but have need for
- k. No, and have no need for

50. Overall, do you feel that your IBD management is well-coordinated? (For example: tests are arranged in a coordinated way, you can see different specialists in the same visit and do not need to come to the hospital on several occasions, etc)

- a. Yes, it is very well coordinated
- b. Yes, it is fairly well coordinated
- c. No, it is fairly uncoordinated
- d. No, it is completely uncoordinated

51. Overall, how would you rate the way the health specialists involved in your IBD care communicate with you?

- a. Excellent
- b. Very good
- c. Good
- d. Fair
- e. Poor

52. In your IBD consultations do you feel that you...

- a. ...can ask all the questions that are important to you?
- b. ...are as involved as you want to be in the decisions about your treatment?
- c. ...have the possibility to ask for a second opinion with regard to treatment options?
 - i. Always
 - ii. Nearly always
 - iii. Sometimes
 - iv. Usually not
 - v. Never

53. In the past 2 years of treating your IBD, was there ever a time when doctors or other health care professionals failed to share important information about your medical history or treatment with each other?

- a. Yes
- b. No
- c. Don't know/Can't remember

54. Overall, how do you rate the quality of the IBD care that you have received in the past 12 months?

- a. Excellent
- b. Very good

- c. Good
- d. Fair
- e. Poor
- f. Did not receive any IBD care in the last 12 months

55. Thinking about your IBD consultations in the last 12 months, overall, have these topics been sufficiently discussed for your needs

- a. Current symptoms
- b. Medical treatments
- c. Surgery
- d. Novel or experimental treatments
- e. Nutrition/Diet
 - i. Yes
 - ii. No
 - iii. Never had a need to discuss
 - iv. Don't know/Can't remember

56. Thinking about your IBD consultations in the last 12 months, overall, have these topics been sufficiently discussed for your needs? Questions arising from your IBD in relation to...

- a. ...practical daily living issues
- b. ...education/studies
- c. ...employment
- d. ...personal relationships
- e. ...sexual relationships
- f. ...general lifestyle issues
 - i. Yes
 - ii. No
 - iii. Never had a need to discuss
 - iv. Don't know/Can't remember

57. How often, after your IBD consultations in the last 12 months, did you feel you <u>did not</u> get to share something about your IBD that may have been important?

- a. Always (100% of the time)
- b. Most of the time (75%–99%)
- c. Much of the time (50%–74%)
- d. Sometimes (25%–49%)
- e. Hardly ever/Never (less than 25% of the time)
- f. Not applicable/don't know

58. During the past 12 months, when you received care, has any health care professional you see for your IBD...

- a. Discussed with you your main goals or priorities in caring for your condition(s)
- b. Helped you make a plan that you could carry out in your daily life
 - i. Yes
 - ii. No
 - iii. Don't know/Can't remember

59. After any of your consultations for your IBD in the last 12 months, have you ever consulted another doctor for a second opinion?

- a. Yes
- b. No
- c. Don't know/Can't remember

60. In your consultations regarding your IBD in the past 12 months, did you ever give your own suggestion for appropriate treatment based on your knowledge and experience?

- a. Yes
- b. No
- c. Don't know/Can't remember

Questions about online behaviour in relation to your health

61. How often do you search for or discuss IBD-related information online?

- a. Never
- b. One or a few times per year
- c. 1–2 times a month
- d. 3–5 times a month
- e. 6–9 times a month
- f. 10 times a month or more

62. How well do you manage to find the information you are looking for when searching online for IBD-related information?

- a. Can always or almost always find the information I'm looking for
- b. Usually find the information I'm looking for
- c. Usually do not find the information I'm looking for
- d. Can never or almost never find the information I am looking for

63. Where do you usually find the IBD-related information you seek online? (Tick all that apply)

- a. Official and publicly sponsored health websites of my own country
- b. National IBD patient association(s)
- c. Online health magazines and publications
- d. International health communities such as Patients Like Me, WebMD
- e. Other health-related online discussion forums
- f. Discussion with friends and acquaintances through social media such as Facebook
- g. Other sources

64. How often do you search for or discuss non-IBD related health information online?

- a. Never
- b. One or a few times per year
- c. 1–2 times a month
- d. 3–5 times a month
- e. 6–9 times a month
- f. 10 times a month or more

65. Have you ever...

- a. Written anything on the internet about your health or care?
- b. Discussed and exchanged experiences about your own health online (such as diet, exercise, or any specific diagnosis)?
- c. Discussed and exchanged experiences about your IBD online?
 - i. Yes, occasionally
 - ii. Yes, frequently
 - iii. No, but can imagine doing so
 - iv. No, and cannot imagine doing so

66. To what extent do you agree with the following statements? Please answer 1–7 1: disagree completely and 7: agree completely

- a. I feel that in order to get the best possible IBD care I must seek information about my condition on my own and actively suggest treatments
- b. The health care system in my country needs to be much better at using modern information technology

67. Have you ever...

- a. Used any mobile phone application related to your health (e.g., fitness, sleep, nutrition)?
- b. Used any mobile phone application related to your IBD?
 - i. Yes, occasionally
 - ii. Yes, frequently
 - iii. No, but can imagine doing so
 - iv. No, and cannot imagine doing so

68. Have you ever...

- a. Looked at your medical record online?
- b. Renewed a prescription online?
- c. Sent or received email from your doctor or nurse?
- d. Communicated with your doctor or nurse through online chat?
 - i. Yes, occasionally
 - ii. Yes, frequently
 - iii. No, but would be interested in doing so if option available
 - iv. No, and I am not interested in doing so

69. Generally speaking, how much confidence do you have in health information from the following sources:

- a. Health information from your favourite online sources
- b. Health information from public news media (newspapers, magazines, TV)
- c. Health information from friends and acquaintances
- d. Health information from your doctor
- e. Health information from IBD patient organisation that you are a member of
 - i. Very low confidence
 - ii. Fairly low confidence
 - iii. Fairly high confidence
 - iv. Very high confidence
 - v. Complete confidence
 - vi. Never get health information from this source

Thank you for your answers so far!

The final questions relate to the future scenario described below:

“Try and imagine this scenario: a time in the future when you can record your symptoms and how you manage your IBD online, share these and discuss them in online communities and then computer programmes analyse everyone’s comments and suggest new treatments or approaches based on what actually seems to work for people rather than the traditional form of clinical research.”

70. In 2020, do you think there will be services similar to the one described above?

- a. No, very unlikely
- b. No, quite unlikely
- c. Yes, quite likely
- d. Yes, very likely

71. If a service such as the one described existed, do you think that you would consult it for advice on health and treatment?

- a. No, definitely not
- b. No, probably not
- c. Yes, probably
- d. Yes, definitely

72. If a service such as the one described existed, can you see yourself being a member of the community and share your own health information?

- a. No, definitely not
- b. No, probably not
- c. Yes, probably
- d. Yes, definitely

73. Do you think that a service such as the one described could contribute to patients getting better care and treatments for their conditions?

- a. No, I think it would cause more harm than good
- b. Yes, I think it would have some positive effect
- c. Yes, I think it would have a large positive effect

74. Do you think that services such as the one described will lessen peoples need to get advice from medical professionals in the future?

- a. Yes, I think that services like the one described in the text will reduce people's need for advice from medical professionals in the future
- b. No, I do not think services like the one described in the text will reduce people's need for advice from medical professionals in the future

Thank you for completing the survey! The information you have given will help to improve services for people with IBD in your country and in others.