

Supplementary Material 1. IRCC enrollment questionnaire.

“In the name of God”

IRCC enrollment questionnaire



شبکه ملی تحقیقات بیماریهای التهابی روده

Patient-reported questions:

Patient Demographic data

1. Date of filling questionnaire:
2. First Name:
3. Last Name:
4. National code:
5. Gender: 1) Male 2) Female
6. Marital status: 1) Single 2) Married
7. Landline Phone:
8. Mobile Phone:
9. Birth Date:
10. Birth province:
11. Birth city:
12. Living province:
13. Living city:
14. Education: 0) illiterate 1) Primary school 2) Middle school 3) High school 4) Associate degree
5) Bachelor 6) Master 7) Doctoral
15. Ethnicity: 1) Fars 2) Turk 3) Lur 4) Kord 6) Arab 7) Turkman 8) Other
16. Twin: 0) No 1) Yes
17. Twin type: 1) Homozygote 2) Hetrozygote
18. Your doctor name:

Past medical History

19. Did you have heart disease? Y/N
20. Did you take medication for it? Y/N
21. Did it limit your activity? Y/N
22. At what age did you get heart disease?
23. Did you have hypertension? Y/N
24. Did you take medication for it? Y/N
25. Did it limit your activity? Y/N
26. At what age did you get hypertension?
27. Did you have lung disease? Y/N
28. Did you take medication for it? Y/N
29. Did it limit your activity? Y/N
30. At what age did you get lung disease?

31. Did you have diabetes? Y/N
32. Did you take medication for it? Y/N
33. Did it limit your activity? Y/N
34. At what age did you get diabetes?
35. Did you have gastric ulcer? Y/N
36. Did you take medication for it? Y/N
37. Did it limit your activity? Y/N
38. At what age did you get gastric ulcer?
39. Did you have kidney disease? Y/N
40. Did you take medication for it? Y/N
41. Did it limit your activity? Y/N
42. At what age did you get kidney disease?
43. Did you have liver disease? Y/N
44. Did you take medication for it? Y/N
45. Did it limit activity? Y/N
46. At what age did you get liver disease?
47. Did you have anemia or any other blood disease? Y/N
48. Did you take medication for it? Y/N
49. Did it limit your activity? Y/N
50. At what age did you get anemia or any other blood disease?
51. Did you had cancer? Y/N
52. Did you take medication for it? Y/N
53. Did it limit your activity? Y/N
54. At what age did you get cancer?
55. Did you have depression? Y/N
56. Did you take medication for it? Y/N
57. Did it limit your activity? Y/N
58. At what age did you get depression?
59. Did you have back pain? Y/N
60. Did you take medication for it? Y/N
61. Did it limit your activity? Y/N
62. At what age did you get back pain?
63. Did you have history of previous TB? Y/N
64. At what age did you get TB?
65. Did you have history of previous HBV? Y/N
66. At what age did you get HBV?
67. Did you have history of previous HIV? Y/N
68. At what age did you get HIV?
69. Did you have history of Appendectomy? Y/N
70. At what age did you appendectomy?

Social History

71. Do you smoke? 1) Never used 2) Currently using 3) Previously using
72. If currently or previously using, how many packet did you use per day?
73. If currently or previously using, at what age did you start smoking?



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74. If previously using, at what age did you stop smoking?
 75. Have you ever used hookah? 1) Never used 2) Currently using 3) Previously using
 76. If currently or previously using, how many days per week did you use hookah?
 77. If currently or previously using, at what age did you start hookah use?
 78. If currently or previously using, at what age did you stop hookah use?
 79. Have you ever used opium?
 1) Never used 2) Currently using 3) Previously using
 80. If currently or previously using, how many days per week did you use opium?
 81. If currently or previously using, at what age did you start opium use?
 82. If previously used, at what age did you stop opium use?
 83. If currently or previously using, how many noxhod per day:
 84. Type of used opium: 1) Teriak 2) Shireh 3) Sukhteh
 85. Rout of administration: 1) Oral 2) Inhaled 3) Both



Family History

86. Is there history of IBD in your family members: Y/N
 87. If yes, which family member: 1) father 2) mother 3) brother 4) sister 7) son 8) daughter
 9) second degree
 88. If yes, what was the type: 1) UC 2) CD 3) Not known which subtype

Symptoms and Signs, function and quality of life

89. Do you believe that your IBD has been well controlled in the past 2 weeks?
 2) Yes 0) No 1) Not sure
 90. Do you believe that your current treatment is useful in controlling your IBD?
 2) Yes 0) No 1) Not sure
 91. Over the past 2 weeks, have your bowel symptoms been getting worse, getting better or not changed? 2) Better 1) No change 0) Worse

In the past 2 weeks, did you:

92. Miss any planned activities because of IBD? 0) Yes 2) No 1) Not sure
 93. Wake up at night because of symptoms of IBD? 0) Yes 2) No 1) Not sure
 94. Suffer from significant pain or discomfort? 0) Yes 2) No 1) Not sure
 95. Often feel lacking in energy? 0) Yes 2) No 1) Not sure
 96. Feel anxious or depressed because of your IBD? 0) Yes 2) No 1) Not sure
 97. Think you needed a change to your treatment? 0) Yes 2) No 1) Not sure

98. Weight (in kilogram):

99. Did you have fistula? 1) No 2) Yes 9) N/A

Treatment Data

100. Have you ever used prednisolone for IBD treatment?
 1) Never used 2) Currently using 3) Previously using
 101. When did you start prednisolone?
 102. When did you finish prednisolone?
 103. Who stop the treatment? 1) Patient 2) Physician

104. If your physician stopped the treatment, what was the reason?
 1) No response 2) Non-compliance 3) Recovery 4) Drug reaction 9) N/A
105. Have you ever used immunomodulator for IBD treatment?
 1) Never used 2) Currently using 3) Previously using
106. What type of immunomodulator did you use?
 1) Azathioprine 2) 6-Mercaptopurin 3) Methotrexate
107. When did you start immunomodulator?
108. When did you finish immunomodulator?
109. Who did stop the treatment? 1) Patient 2) Physician
110. If your physician stopped the treatment, what was the reason?
 1) No response 2) Non-compliance 3) Recovery 4) Drug reaction 9) N/A
111. Have you ever used 5-ASA for IBD treatment?
 1) Never used 2) Currently using 3) Previously using
112. What type of 5-ASA did you use? 1) Sulfasalazine 2) Mesalazine
113. When did you start 5-ASA?
114. When did you finish 5-ASA?
115. Who did stop the treatment? 1) Patient 2) Physician
116. If your physician stopped the treatment what was the reason?
 1) No response 2) Non-compliance 3) Recovery 4) Drug reaction 9) N/A
117. Have you ever used anti-TNF for IBD treatment?
 1) Never used 2) Currently using 3) Previously using
118. What type of anti-TNF did you use? 1) Infliximab 2) Adalimumab
119. When did you start anti-TNF?
120. When did you finish anti-TNF?
121. Who did stop the treatment? 1) Patient 2) Physician
122. If your physician stopped the treatment what was the reason?
 1) No response 2) Non-compliance 3) Recovery 4) Drug reaction 9) N/A



Healthcare utilization & Treatment complication

123. What was the total number of emergency room visits in past 12 months?
124. How many days was the IBD-related admissions in past 12 months?
125. Did you use steroid in previous 12 months ago? Y/N
126. Was the duration of steroid use more than 3 months? Y/N
127. Was there any admission after 3 months of starting treatment? Y/N

Survival and Disease control

128. Was your IBD in remission in last 6 months?
 In the last 6 months, my disease has been
- 0 = Constantly active, giving me symptoms every day
 - 1 = Often active, giving me symptoms most days
 - 2 = Sometimes active, giving me symptoms on some days [for instance 1–2 days/week]
 - 3 = Occasionally active, giving me symptoms 1–2 days/month
 - 4 = Rarely active, giving me symptoms on a few days in the past 6 months

5 = I was well in the past 6 months: what I consider a remission or absence of symptoms

129. Did you have colorectal cancer after suffering from IBD? Y/N

130. What was the diagnosis date of colorectal cancer?



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Clinician-reported questions

General clinical Data

1. Date of Diagnosis:
2. Final Diagnosis: 1) UC 2) CD 3) IBD unclassified
3. If UC what is disease extent: 1) Proctitis 2) Left sided colitis 3) Pancolitis 9) N/A
4. If Crohn's what is disease location: 1) Ileal 2) Colonic 3) Ileocolonic 4) Isolated upper GI 9) N/A
5. If Crohn's what is disease behavior: 1) Non-fistulizing 2) Fistulizing 3) Strictureing 9) N/A
6. Are there any extra-intestinal manifestations?
 - 1) Primary sclerosing cholangitis 2) Autoimmune hepatitis 3) Gallbladder stone 4) Uveitis 5) Erythema nodosum 6) Pyoderma gangrenous 7) Peripheral arthritis 8) Ankylosing spondylitis 9) N/A

Surgery data

7. Did you have surgery due to IBD disease? Y/N
8. If UC, what type of surgery have you done?
 - 1) Proctocolectomy with ileal pouch-anal anastomosis 2) Total abdominal colectomy with ileorectal anastomosis 3) Total abdominal colectomy with end ileostomy 9) N/A
9. If CD, what type of surgery have been done?
 - 1) Resection 2) Fistulectomy and Abscess drainage 9) N/A