

**Supplementary Table 1 Disease knowledge and medical therapy adherence questionnaire**

**HEALTH CONTACT**

1. Have you sought out and obtained an adult physician to follow you closely?

☐ YES ☐ Adult Gastroenterologist ☐ Family Physician

Name(s) of the physician(s):

☐ NO Why not? ☐ I don't need one ☐ I can't find one ☐ Others:

**HEALTH STATUS**

1. Do you have: ☐ Ulcerative Colitis (UC) ☐ Crohn's Disease (CD) ☐ I don't know

2. Where is the disease located?

UC: ☐ Rectum ☐ Left colon ☐ Extensive/Pancolitis ☐ I don't know

CD: ☐ Ileocolonic (small & large bowel) ☐ Colonic (large bowel) ☐ Ileal (small bowel)

☐ Upper GI ☐ I don't know

3. When were you diagnosed? \_\_\_\_\_ years old ☐ I don't know

4. Have you had surgery for IBD? ☐ Yes ☐ No ☐ I don't know

**MEDICATIONS & BLOODWORKS**

1. What medications are you taking now?

☐ 5-ASA/Mesalamine (Asacol, Pantasa, Salofalk) ☐ Azathioprine (Imuran) /6-MP

(Purinethol)

☐ Methotrexate ☐ Infliximab (Remicade) ☐ Adalimumab (Humira) ☐ Others ☐ I

don't know

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2. How often do you **forget** to take your medication?

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5-ASA/Mesalamine      ☐ 0 – 30%   ☐ 30 – 50%   ☐ >50%   ☐ Not Applicable   ☐ I don't know

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Azathioprine/6-MP      ☐ 0 – 30%   ☐ 30 – 50%   ☐ >50%   ☐ Not Applicable   ☐ I don't know

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Methotrexate      ☐ 0 – 30%   ☐ 30 – 50%   ☐ >50%   ☐ Not Applicable   ☐ I don't know

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Infliximab/ Adalimumab   ☐ 0 – 30%   ☐ 30 – 50%   ☐ >50%   ☐ Not Applicable   ☐ I don't know

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Others      ☐ 0 – 30%   ☐ 30 – 50%   ☐ >50%   ☐ Not Applicable   ☐ I don't know

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3. Do you have to do regular blood work?      ☐ Yes   ☐ No   ☐ I don't know

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4. How often do you **forget** to do the required bloodwork?

☐ 0 – 30%   ☐ 30 – 50%   ☐ >50%   ☐ I don't know

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We would like to find out how you have been doing since your **last visit at BC Children's Hospital**.

**Supplementary Table 2 Beliefs about Medicine Questionnaire<sup>1</sup>**

SPECIFIC ITEMS				
1. My current health depends on my medicines (N)				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Uncertain	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
2. Having to take medicines worries me (C)				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Uncertain	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
3. My life would be impossible without my medicines (N)				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Uncertain	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
4. I sometimes worry about the long term effects of my medicines (C)				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Uncertain	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
5. Without my medicines I would be very sick (N)				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Uncertain	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
6. My medicines are a mystery to me (C)				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Uncertain	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
7. My health in the future will depend on my medicines (N)				

☐ Strongly disagree      ☐ Disagree      ☐ Uncertain      ☐ Agree      ☐ Strongly agree

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8. My medicine disrupt my life (C)

☐ Strongly disagree      ☐ Disagree      ☐ Uncertain      ☐ Agree      ☐ Strongly agree

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9. I sometimes worry about becoming too dependent on my medicines (C)

☐ Strongly disagree      ☐ Disagree      ☐ Uncertain      ☐ Agree      ☐ Strongly agree

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10. My medicines protect me from becoming worse (N)

☐ Strongly disagree      ☐ Disagree      ☐ Uncertain      ☐ Agree      ☐ Strongly agree

### GENERAL ITEMS

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1. Doctors use too many medicines (O)

☐ Strongly disagree      ☐ Disagree      ☐ Uncertain      ☐ Agree      ☐ Strongly agree

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2. People who take medicines should stop their treatment for a while every now and then (O)

☐ Strongly disagree      ☐ Disagree      ☐ Uncertain      ☐ Agree      ☐ Strongly agree

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3. Medicines are addictive (H)

☐ Strongly disagree      ☐ Disagree      ☐ Uncertain      ☐ Agree      ☐ Strongly agree

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disagree				agree
<hr/>				
4. Medicines do more harm than good (H)				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Uncertain	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
<hr/>				
5. All medicines are poisons (H)				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Uncertain	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
<hr/>				
6. Doctors place too much trust on medicine (O)				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Uncertain	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
<hr/>				
7. If doctors had more time with patients, they would prescribe fewer medicines (O)				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Uncertain	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
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<sup>1</sup>(N) demotes questions counted as necessity; (C) denotes questions counted as concern; (O) denotes questions counted as overuse; (H) denotes questions counted as harm. We would like to ask you about your personal views about your medicine and medicine in general. Please check (✓) how you feel about each of the statements. There is no right or wrong answer; we are interested in your personal views.