Quality of Life Survey

The following questions are being asked about your child’s inflammatory bowel disease condition.

1. How often did/does your child show a lack of energy:

- BEFORE surgery?
  - Never
  - Sometimes
  - Often
  
<table>
<thead>
<tr>
<th>Never</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
</tbody>
</table>

- CURRENTLY?
  - Never
  - Sometimes
  - Often
  
<table>
<thead>
<tr>
<th>Never</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
</tbody>
</table>

2. How often did/does your child have stomach aches, pains or bloating:

- BEFORE surgery?
  - Never
  - Sometimes
  - Often
  
<table>
<thead>
<tr>
<th>Never</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
</tbody>
</table>

- CURRENTLY?
  - Never
  - Sometimes
  - Often
  
<table>
<thead>
<tr>
<th>Never</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
</tbody>
</table>

3. My child had/has limitations due to feeling sick:

- BEFORE surgery?
  - Never
  - Sometimes
  - Often
  
<table>
<thead>
<tr>
<th>Never</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
</tbody>
</table>

- CURRENTLY?
  - Never
  - Sometimes
  - Often
  
<table>
<thead>
<tr>
<th>Never</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
</tbody>
</table>

4. How did/does your child’s condition affect your family:

- BEFORE surgery?
  - Good affect
  - No affect
  - Bad affect
  
<table>
<thead>
<tr>
<th>Good affect</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
</tbody>
</table>

- CURRENTLY?
  - Good affect
  - No affect
  - Bad affect
  
<table>
<thead>
<tr>
<th>Good affect</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
</tbody>
</table>
5. How often did/does your child’s condition restrict what he/she eats:

- BEFORE surgery?
  - Never
  - Sometimes
  - Often

- CURRENTLY?
  - Never
  - Sometimes
  - Often

6. My child missed/misses school because of his/her disease:

- BEFORE surgery?
  - Never
  - Sometimes
  - Often

- CURRENTLY?
  - Never
  - Sometimes
  - Often

7. My child was/is unhappy about the way he/she looks:

- BEFORE surgery?
  - Never
  - Sometimes
  - Often

- CURRENTLY?
  - Never
  - Sometimes
  - Often

8. My child was/is unhappy with his/her life:

- BEFORE surgery?
  - Never
  - Sometimes
  - Often

- CURRENTLY?
  - Never
  - Sometimes
  - Often

9. How often did/does your child have to miss out on social events (play, sports, parties) because of his/her disease:

- BEFORE surgery?
  - Never
  - Sometimes
  - Often

- CURRENTLY?
  - Never
  - Sometimes
  - Often
10. How would you describe your child’s growth compared to his/her peers:

- **BEFORE surgery?**
  - Similar
  - Slightly below
  - Very below
  
<table>
<thead>
<tr>
<th>Similar</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>

- **CURRENTLY?**
  - Similar
  - Slightly below
  - Very below
  
<table>
<thead>
<tr>
<th>Similar</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>
Disease Severity Survey

1. On average, how many stools per day did/does your child have:
   
   A.  i.  BEFORE surgery? __________________
   ii.  6 months AFTER surgery? _______________
   iii. 1 year AFTER surgery? _______________
   iv.  2 years AFTER surgery? _______________
   v.  CURRENTLY? __________________

   B.  How many involuntary BM (accidents) does the patient have during the day? _______

   C.  How many involuntary BM (accidents) does the patient have during the night (while sleeping)?__________

   D.  How many voluntary BM does the patient have during the day and night (total)? _______

   E.  During the day to control bowel management, not urine, does the patient wear diapers/depends? __________

   F.  During the night (while sleeping) to control bowel management, not urine, does the patient wear diapers/depends? __________

   G.  Does the patient have perineal skin breakdown (rash)? __________

   H.  Do you currently take any of the following? If so what dose (how much)?
      i.  Loperamide (Imodium)
      ii.  Diphenoxylate & Atropine (Lomotil)
      iii. Dose _______________________

2. Did/does your child’s stools contain blood:
   ➢ BEFORE surgery?
     Never
     0 1 2 3 4 5 6 7 8 9 10
     Sometimes
   ➢ CURRENTLY?
     Never
     0 1 2 3 4 5 6 7 8 9 10
     Sometimes

3. What IBD associated symptoms has your child experienced:
   ➢ BEFORE surgery (select all that apply)?
     □ None
     □ Arthralgia (joint pain)
□ Uveitis (eye inflammation)
□ Aphthous ulcers (mouth ulcers or canker sores)
□ Erythema nodosum (a condition with tender, red skin nodules)
□ Pyoderma gangrenosum (a condition causing ulceration of skin)
□ Anal fissure (break or tear in the skin at the anal canal)
□ Perianal abscess (infection)
□ Fistula (abnormal connection of intestine to the bladder/vagina/urinary tract/skin or other intestine)
□ Intra-abdominal abscess (infection)
□ Bowel stricture (narrowing of intestine)
□ Bowel obstruction (intestinal obstruction/blockage)
□ Other (please specify)_________________________________________

> CURRENTLY (select all that apply)?
□ None
□ Arthralgia (joint pain)
□ Uveitis (eye inflammation)
□ Aphthous ulcers (mouth ulcers or canker sores)
□ Erythema nodosum (a condition with tender, red skin nodules)
□ Pyoderma gangrenosum (a condition causing ulceration of skin)
□ Anal fissure (break or tear in the skin at the anal canal)
□ Perianal abscess (infection)
□ Fistula (abnormal connection of intestine to the bladder/vagina/urinary tract/skin or other intestine)
□ Intra-abdominal abscess (infection)
□ Bowel stricture (narrowing of intestine)
□ Bowel obstruction (intestinal obstruction/blockage)
□ Other (please specify)_________________________________________

4. Has your child been prescribed the following medications for IBD:

> BEFORE surgery (select all that apply)?
□ Oral steroids (prednisone, prednisolone, methylprednisolone, hydrocortisone, dexamethasone, budesonide, Orapred, Cortef)
□ Oral 5-aminosalicylic acid (5-ASA, Mesalamine, Pentasa, Asacol, Lialda, Apriso)
□ Sulfasalazine (Azulfidine)
□ Azathioprine (Imuran, Azasan)
□ Mercaptopurine (6MP, Purinethol)
□ Methotrexate (Rheumatrex, Trexall, Amethopterin, MTX)
□ Anti-TNF-alpha (Remicade, Humira, Cimzia, Infliximab, Adalimumab, Certolizumab)
□ Loperamide (Imodium)
□ Diphenoxylate & Atropine (Lomotil)

> CURRENTLY (select all that apply)?
□ Oral steroids (prednisone, prednisolone, methylprednisolone, hydrocortisone, dexamethasone, budesonide, Orapred, Cortef)
□ Oral 5-aminosalicylic acid (5-ASA, Mesalamine, Pentasa, Asacol, Lialda, Apriso)
□ Sulfasalazine (Azulfidine)
□ Azathioprine (Imuran, Azasan)
□ Mercaptopurine (6MP, Purinethol)
□ Methotrexate (Rheumatrex, Trexall, Amethopterin, MTX)
□ Anti-TNF-alpha (Remicade, Humira, Cimzia, Infliximab, Adalimumab, Certolizumab)
□ Loperamide (Imodium)
□ Diphenoxylate & Atropine (Lomotil)
□ None

5. Has your child experienced any of the following:

> AFTER surgery (select ALL that apply)?
□ Wound infection
□ Anastomotic leak (leak at site of reconnected bowel)
Anastomotic stenosis (narrowing at reconnected bowel)
Intra-abdominal abscess (infection within abdomen)
 Fistula (abnormal connection of intestine to the bladder/vagina/urinary tract/skin or other intestine)
 Incisional hernia
 Bowel stricture (narrowing of intestine)
 Bowel obstruction (intestinal obstruction/blockage)
 Pouchitis (inflammation of surgically created intestinal pouch)
 Need for permanent ostomy (surgical connection between bowel and skin)
 Removal of intestinal pouch (surgical pouch created from intestine)
 Need for unplanned, additional surgery (list surgeries & dates) 

Surgeries performed outside of CCHMC (list surgeries & dates) 

6. Did your child’s IBD symptoms improve AFTER surgery?

<table>
<thead>
<tr>
<th>Complete improvement</th>
<th>Some improvement</th>
<th>No improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>9</td>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>

7. Would you recommend surgical treatment to others with IBD?

<table>
<thead>
<tr>
<th>Yes</th>
<th>Maybe</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>9</td>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>

For the following questions, “planned” IBD surgery refers to ALL planned surgeries to complete a bowel resection in Crohn’s disease or  colectomy and ileoanal reconstruction in Ulcerative Colitis i.e., 1 Stage (1) colectomy with ileal pouch creation, 2 Stage (1) colectomy with ileal pouch creation and ileostomy, (2) closure of ileostomy or 3 Stage (1) colectomy with ileostomy, (2) ileal pouch creation with ileostomy, (3) closure of ileostomy.

8. How many hospital admissions did your child experience:

- BEFORE his/her planned, initial IBD surgery? __________________________
- BETWEEN his/her planned, IBD surgeries? __________________________
- AFTER his/her planned, final IBD surgery? __________________________

9. How many Emergency Department visits and/or emergent hospital admissions did your child experience:

- BEFORE his/her planned, initial IBD surgery? __________________________
- BETWEEN his/her planned, IBD surgeries? __________________________
➢ AFTER his/her planned, final IBD surgery? _____________________

Please use this space to provide any additional comments that you feel is important regarding your child’s condition of inflammatory bowel disease:

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
Appendix A (Patient)  
IBD Surgically Managed

Date completed: ____________  

Method of survey (circle one): phone / mail / e-mail  

Patient: ________________________  
Survey completed by patient now ≥ 18 years old

Quality of Life Survey  
The following questions are being asked about your inflammatory bowel disease condition.

1. How often did/do you show a lack of energy:

   ➢ BEFORE surgery?  
   Never | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
   ➢ CURRENTLY?  
   Never | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10

2. How often did/do you have stomach aches, pains or bloating:

   ➢ BEFORE surgery?  
   Never | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
   ➢ CURRENTLY?  
   Never | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10

3. I had/have limitations due to feeling sick:

   ➢ BEFORE surgery?  
   Never | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
   ➢ CURRENTLY?  
   Never | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10

4. How did/does your condition affect your family:

   ➢ BEFORE surgery?  
   Good affect | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
   No affect | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
   Bad affect | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
   ➢ CURRENTLY?  
   Good affect | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
   No affect | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
   Bad affect | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
5. How often did/does your condition restrict what you eat:

- BEFORE surgery?
  - Never
  - Sometimes
  - Often

- CURRENTLY?
  - Never
  - Sometimes
  - Often

6. I missed/miss school because of my disease:

- BEFORE surgery?
  - Never
  - Sometimes
  - Often

- CURRENTLY?
  - Never
  - Sometimes
  - Often

7. I was/am unhappy about the way I look:

- BEFORE surgery?
  - Never
  - Sometimes
  - Often

- CURRENTLY?
  - Never
  - Sometimes
  - Often

8. I was/am unhappy with my life:

- BEFORE surgery?
  - Never
  - Sometimes
  - Often

- CURRENTLY?
  - Never
  - Sometimes
  - Often

9. How often did/do you have to miss out on social events (play, sports, parties) because of your disease:

- BEFORE surgery?
  - Never
  - Sometimes
  - Often

- CURRENTLY?
  - Never
  - Sometimes
  - Often
10. How would you describe your growth compared to your peers:

- **BEFORE surgery?**
  - Similar: 0
  - Slightly below: 1, 2, 3
  - Very below: 4, 5, 6, 7, 8, 9, 10

- **CURRENTLY?**
  - Similar: 0
  - Slightly below: 1, 2, 3
  - Very below: 4, 5, 6, 7, 8, 9, 10
Disease Severity Survey

1. On average, how many stools per day did/do you have:
   - BEFORE surgery? _________________
   - 6 months AFTER surgery? _________________
   - 1 year AFTER surgery? _________________
   - 2 years AFTER surgery? _________________
   - CURRENTLY? _________________

2. Did/do your stools contain blood:
   - BEFORE surgery?
     - Never
     - Sometimes
     - Often
       - Never
       - Sometimes
       - Often

3. What IBD associated symptoms have you experienced:
   - BEFORE surgery (select all that apply)?
     - None
     - Arthralgia (joint pain)
     - Uveitis (eye inflammation)
     - Aphthous ulcers (mouth ulcers or canker sores)
     - Erythema nodosum (a condition with tender, red skin nodules)
     - Pyoderma gangrenosum (a condition causing ulceration of skin)
     - Anal fissure (break or tear in the skin at the anal canal)
     - Perianal abscess (infection)
     - Fistula (abnormal connection of intestine to the bladder/vagina/urinary tract/skin or other intestine)
     - Intra-abdominal abscess (infection)
     - Bowel stricture (narrowing of intestine)
     - Bowel obstruction (intestinal obstruction/blockage)
     - Other (please specify) ________________________________
   - CURRENTLY (select all that apply)?
     - None
     - Arthralgia (joint pain)
     - Uveitis (eye inflammation)
     - Aphthous ulcers (mouth ulcers or canker sores)
     - Erythema nodosum (a condition with tender, red skin nodules)
     - Pyoderma gangrenosum (a condition causing ulceration of skin)
     - Anal fissure (break or tear in the skin at the anal canal)
     - Perianal abscess (infection)
     - Fistula (abnormal connection of intestine to the bladder/vagina/urinary tract/skin or other intestine)
     - Intra-abdominal abscess (infection)
     - Bowel stricture (narrowing of intestine)
     - Bowel obstruction (intestinal obstruction/blockage)
     - Other (please specify) ________________________________
4. **Have you been prescribed the following medications for IBD:**

   **BEFORE surgery (select all that apply)?**
   - Oral steroids (prednisone, prednisolone, methylprednisolone, hydrocortisone, dexamethasone, budesonide, Orapred, Cortef)
   - Oral 5-aminosalicylic acid (5-ASA, Mesalamine, Pentasa, Asacol, Lialda, Apriso)
   - Sulfasalazine (Azulfidine)
   - Azathioprine (Imuran, Azasan)
   - Mercaptopurine (6MP, Purinethol)
   - Methotrexate (Rheumatrex, Trexall, Amethopterin, MTX)
   - Anti-TNF-alpha (Remicade, Humira, Cimzia, Infliximab, Adalimumab, Certolizumab)
   - Loperamide (Imodium)
   - Diphenoxylate & Atropine (Lomotil)

   **CURRENTLY (select all that apply)?**
   - Oral steroids (prednisone, prednisolone, methylprednisolone, hydrocortisone, dexamethasone, budesonide, Orapred, Cortef)
   - Oral 5-aminosalicylic acid (5-ASA, Mesalamine, Pentasa, Asacol, Lialda, Apriso)
   - Sulfasalazine (Azulfidine)
   - Azathioprine (Imuran, Azasan)
   - Mercaptopurine (6MP, Purinethol)
   - Methotrexate (Rheumatrex, Trexall, Amethopterin, MTX)
   - Anti-TNF-alpha (Remicade, Humira, Cimzia, Infliximab, Adalimumab, Certolizumab)
   - Loperamide (Imodium)
   - Diphenoxylate & Atropine (Lomotil)
   - None

5. **Have you experienced any of the following:**

   **AFTER surgery (select ALL that apply)?**
   - Wound infection
   - Anastomotic leak (leak at site of reconnected bowel)
   - Anastomotic stenosis (narrowing at reconnected bowel)
   - Intra-abdominal abscess (infection within abdomen)
   - Fistula (abnormal connection of intestine to the bladder/vagina/urinary tract/skin or other intestine)
   - Incisional hernia
   - Bowel stricture (narrowing of intestine)
   - Bowel obstruction (intestinal obstruction/blockage)
   - Pouchitis (inflammation of surgically created intestinal pouch)
   - Need for permanent ostomy (surgical connection between bowel and skin)
   - Removal of intestinal pouch (surgical pouch created from intestine)
   - Need for unplanned, additional surgery (list surgeries & dates) ________________________________
   - Surgeries performed outside of CCHMC (list surgeries & dates) ________________________________

6. **Did your IBD symptoms improve **AFTER surgery?**

<table>
<thead>
<tr>
<th>Complete improvement</th>
<th>Some improvement</th>
<th>No improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>9</td>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>
7. Would you recommend surgical treatment to others with IBD?

Yes
0 1 2 3 4 5 6 7 8 9 Never

For the following questions, “planned” IBD surgery refers to ALL planned surgeries to complete a bowel resection in Crohn’s disease or colectomy and ileal anal reconstruction in Ulcerative Colitis i.e., 1 Stage (1) colectomy with ileal pouch creation, 2 Stage (1) colectomy with ileal pouch creation and ileostomy, (2) closure of ileostomy or 3 Stage (1) colectomy with ileostomy, (2) ileal pouch creation with ileostomy, (3) closure of ileostomy.

8. How many hospital admissions did you experience:

➢ BEFORE your planned, initial IBD surgery? _____________________
➢ BETWEEN your planned, IBD surgeries? _____________________
➢ AFTER your planned, final IBD surgery? _____________________

9. How many Emergency Department visits and/or emergent hospital admissions did you experience:

➢ BEFORE your planned, initial IBD surgery? _____________________
➢ BETWEEN your planned, IBD surgeries? _____________________
➢ AFTER your planned, final IBD surgery? _____________________

Please use this space to provide any additional comments that you feel is important regarding your condition of inflammatory bowel disease:

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________

13