

**Supplementary Information:****Survey 1: Individual IBD Nurse Data**

Q1: Name

Q2: Email address

Q3: What is the name of the Trust or organisation who employs you?

Q4: What is the name of the hospital you work in?

Q5: In which country are you working?

Q6: What is your job title?

Q7: What Band are you?

Q8: What area of care do you work in?

Q9: How long have you been in your current post?

Q10: How long have you had a specialist nursing role in IBD?

Definition of IBD Nurse Specialist - A nurse with advanced or specialist expertise, that leads and manages a caseload of patients, providing diagnoses, care planning, treatment and follow up and continuity of care.

Q11: What are your total contracted hours per week?

Q12: Do you have any other clinical responsibilities besides IBD care?

Q13: Which other areas of clinical responsibility do you have? (choose as many as applicable)

Q14: Approximately, what percentage of your working time is spent in clinical IBD nursing care?

Q15: Your qualifications

Q16: Does your role include answering a telephone / email advice line?

Q17: Have you had any formal training on managing advice lines?

Q18: On a scale of 1-10 (1=not stressful, 10=extremely stressful) how stressful do you find managing the advice line?

Q19: Do you receive nursing clinical supervision (time with a skilled supervisor to reflect on the care you give)

Q20: In your absence, is the advice line suspended?

Q21: Do you regularly sign post your patients (whether newly diagnosed or not) to information supplied by Crohn's and Colitis UK?

Q22: Do you order free patient packs from the Crohn's and Colitis UK's online information ordering system?

Q23: Do you currently take up Crohn's and Colitis UK's offer for free membership to all IBD nurse specialists?

Q24: Do you attend an IBD network regional nursing group?

Q25: If yes, which one?

Q26: If no, would you like to know about your nearest regional group?

Q27: Are you a member of the RCN?

Q28: Are you a member of the RCN Gastrointestinal Forum

Q29: Do you follow the RCN Facebook pages?

### **Survey 2: IBD Nursing Services Survey**

Q1: Name

Q2: Email

Q3: What is the name of the Trust or organisation where your service is based.

Q4: Where is your IBD nursing service based? (if over several sites, please select more than one)

Q5: What population does your service serve? (this information can be obtained from your general manager, JAG visits to endoscopy, or lead clinician)

Q6: Across how many sites do your team provide services?

Q7: How many whole time equivalent specialist nurses are employed to deliver the IBD nursing service. Definition of IBD Nurse Specialist. A nurse with advanced or specialist expertise, that leads and manages a caseload of patients, providing diagnoses, care planning, treatment and follow up and continuity of care.(This does not include nurses who solely administer biologic therapies).

Q8: Over that last 2 years, has the establishment (number of funded posts) in your IBD specialist nursing service changed?

Q9: If the establishment has increased, how many extra nursing posts have been funded?

Q10: If your establishment increased, did support from Isobel Mason or the Crohn's and Colitis UK Nurses Campaign help?

Q11: If the establishment has increased, would you be willing to share any successful job descriptions / business cases with other IBD services?

Q12: If the establishment has decreased, how many posts are no longer funded?

Q13: Are you aware of the new caseload recommendations for IBD nurse specialist numbers (2.5 wte per 250,00 population or max 500 patients per nurse)

Q14: Do you currently have a business case for more nursing posts under development?

Q15: Would you like more support to develop a business case?

Q16: Do you currently have any vacancies for IBD specialist nursing posts?

Q17: Does your service have a patient panel?

Q18: How long has the IBD patient panel been in existence?

Q19: Who leads the patient panel?

Q20: Does your nursing service have identified administrative support?

Q21: If you have administrative support, how has the resource changed in the past 2 years?

Q22: What is your nurse specialist service role in Biologics pathways. (select as many as apply)?

Q23: Approximately, how many patients do you have on infliximab?

Q24: Approximately, how many patients do you have on Adalimumab?

Q25: Approximately, how many patients do you have on Vedolizumab?

Q26: Have you used any of the following other biologic therapies?

Q27: Does your service run a biologic specific MDT?

Q28: Does your IBD service have patients entered onto the IBD Registry?

Q29: If you do have patients entered into the IBD Registry, who entered the data (tick as many as apply)?

Q30: What types of clinics does your IBD nurse specialist service provide? (tick as many as apply)

Q31: Do you have contact with a Crohn's and Colitis UK local network group?

Q32: How often do you, or one of your nursing team, meet with your Crohn's and Colitis UK Network Group?

Q33: What does your nursing service do to support your Crohn's and Colitis UK Local Network Group (tick all that apply)

Q34: How much time (approx) do you, or a member of your team, spend per month supporting your Crohn's and Colitis UK Local Network Group?

Q35: Are your service details entered onto the Crohn's and Colitis UK 'Find an IBD Nurse' map? (check at <https://www.Crohn'sandcolitis.org.uk/support/find-an-ibd-nurse-specialist>)

Q36: What would be the most helpful support Crohn's and Colitis UK could give you to develop your service?