Project document 1 – Healthcare professional questionnaire

[Please note that this questionnaire was hosted online via the Qualtrics platform and therefore the visual appearance was different, and this also included routing through different question options, as appropriate.]

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picase specify)		
5. In which year were you appointed as a Consultant or Specialist Nurse?		
ve personal experience of IBD?		
have IBD		
One of my family or friends has IBD		
•		
not to say		

Centre and caseload – Section B

5. Which of the following best describes IBD services in your centre?

- Secondary referral service from primary care/inpatient specialities
- o Tertiary referral service from gastrointestinal/ surgery services outside of your hospital
- o Quaternary referral service referrals from other specialist (tertiary) centres

6. In which region is your hospital situated?

- o North East
- North West
- Yorkshire and the Humber
- o East Midlands
- West Midlands
- East of England
- o London

- South East
- o South West
- o Scotland
- o Northern Ireland
- Wales

7.	Is there a Multi-Disciplinary Team (MDT) that provides care to patients with IBD in your
	organisation?

- o Yes
- o No
- o Unsure

0	If yes, who attends the MDT meeting on a regular basis? (please tick all that apply and
	estimate the approximate number of each staff who attend)

mat	e the approximate number of each staff who attend)
0	Consultant Gastroenterologist
0	IBD Specialist Nurse
0	Consultant Radiologist
0	Consultant Histopathologist
0	Consultant Colorectal Surgeon
0	Dietician
0	Pharmacist
0	Psychologist
0	Trainee Gastroenterologist
0	Trainee Radiologist
0	Trainee Colorectal Surgeon
0	Other (please specify title AND number)

8. How much of your clinical time is devoted to supporting/caring for patients with IBD?

- o None of your time
- Very little of your time
- o Some of your time
- o The majority of your time
- o All of your time

9. Which guidelines or standards do you use to inform your management of patients with ulcerative colitis? (please tick all that apply)

- o Locally developed NHS Trust guidelines
- o NICE Clinical Guideline for Ulcerative Colitis (CG166)
- NICE Technology Appraisal Guidance: Infliximab, adalimumab and golimumab for treating moderately to severely active ulcerative colitis after the failure of conventional therapy (TA329)
- NICE Technology Appraisal Guidance: Vedolizumab for treating moderately to severely active ulcerative colitis (TA342)
- NICE Technology Appraisal Guidance: Tofacitinib for moderately to severe active ulcerative colitis (TA547)
- o British Society of Gastroenterology (BSG) Mowat et al. (2011) Guidelines for the management of inflammatory bowel disease

 European Crohn's and Colitis (ECCO) Ulcerative Colitis Consensus Guideline (2017) I don't refer to any guidelines Other (please specify)
Definitions of steroid resistance – Section C
There is no universally adopted definition of corticosteroid resistance in ulcerative colitis. We are keen to get your views on optimal/possible ways of defining this. Thinking about your normal clinical practice:
10. Please record your level of agreement with the following statements.
Note: If you disagree with the statements, you will be given the opportunity to build your own definition of corticosteroid resistance at 10.3, and tell us any additional information.
10.1 Corticosteroid resistance constitutes an incomplete response to prednisolone 40mg/day (or equivalent) after 2 weeks Strongly disagree Disagree
 Neither agree or disagree
AgreeStrongly agree
10.2 Corticosteroid resistance constitutes an incomplete response to prednisolone 40mg/day (or equivalent) after 4 weeks
Strongly disagreeDisagree
 Neither agree or disagree
AgreeStrongly agree
10.3 If you disagree, please circle your response from the choices given to formulate your definition of steroid resistance:
Corticosteroid resistance constitutes an [incomplete / partial / absent] [response / improvement] to [prednisolone / equivalent treatments] of [at least 20mg/day / 30mg/day / 40mg/day] after [1 week / 2 weeks / 3 weeks / 4 weeks / 5 weeks / 6 weeks]
Please use the box below to provide more information about how you define corticosteroid resistance.

11. Does o	corticosteroid resistance include any patients who go into clinical remission after
	ng prednisolone treatment, but then relapse on corticosteroid reduction?
0	Yes
0	No
0	Unsure
[If no]	
In this situ	ation, after what period of remission would you consider a relapse to require or allow
different o	ptions for treatment to those who do not respond fully to systemic corticosteroids? (please
tick)	

	Yes	No	Unsure
2 weeks			
4 weeks			
3 months			
6 months			
The situations should			
be managed			
identically after any			
interval			

Please use the box below to provide more information about how you define corticosteroid
<u>dependence</u> .

T	'reatm	ent	pathwa	$\mathbf{v}\mathbf{s} - \mathbf{S}$	ection	D
	ıcauıı		vaurwa	v 3 — 13	CCHUII	

This section (questions 12-14) will ask about your treatment preferences for patients who are steroid resistant or steroid dependent. Statements describing typical patient scenarios are given. For each of these, you are asked to indicate which treatments you would use for patients who are on thiopurine, and then those who are not on thiopurine.

12.1.1 ULCERATIVE COLITIS: CORTICOSTEROID RESISTANT - ON THIOPURINE

In treating a patient with ulcerative colitis, which additional treatment(s) (assuming that all of these are available in your centre) would you offer to someone with moderately severe disease and with no - or inadequate - response to systemic, out-patient corticosteroid treatment?

(Please tick all that apply)

	(* ************************************
	If the patient already on thiopurine
5-ASA (aminosalicylate)	
Adalimumab	
Admit for IV steroids	
Golimumab	
Infliximab	
Methotrexate (withdrawing thiopurine if on it)	
Surgery	
Tacrolimus	
Tofacitinib	
Vedolizumab	
Other (please specify)	
1	1

12.1.2 ULCERATIVE COLITIS: CORTICOSTEROID RESISTANT ON THIOPURINE

	Treatment
1.	
2.	
3.	
4.	
5.	

12.2.1 ULCERATIVE COLITIS: CORTICOSTEROID RESISTANT - NOT ON THIOPURINE

In treating a patient with ulcerative colitis, which additional treatment(s) (assuming that all of these are available in your centre) would you offer to someone with moderately severe disease and with no, or inadequate, response to systemic, out-patient corticosteroid treatment?

(Please tick all that apply) Thiopurine naïve 5-ASA (aminosalicylate) Adalimumab Adalimumab plus thiopurine* or methotrexate Admit for IV steroids Golimumab Golimumab plus thiopurine* or methotrexate Infliximab Infliximab plus thiopurine* or methotrexate Methotrexate (withdrawing thiopurine if on it) Surgery **Tacrolimus** Thiopurine* Tofacitinib Vedolizumab Vedolizumab plus thiopurine* or methotrexate Other (please specify)

12.2.2 ULCERATIVE COLITIS: CORTICOSTEROID RESISTANT - NOT ON THIOPURINE

	Treatment
1.	
3.	
3.	
4.	
5.	

^{*}Assuming TPMT satisfactory

13.1.1 ULCERATIVE COLITIS: CORTICOSTEROID DEPENDENT - ON THIOPURINE

In treating a patient with ulcerative colitis, what treatments (assuming that all of these are available in your centre) would you offer either alone or in combination for someone with moderately severe disease, who responds to steroids, but rapidly relapses when the dose is reduced?

(Please tick all that apply)

	If the patient already on thiopurine
5-ASA (aminosalicylate)	on anoparine
Adalimumab	
Admit for IV steroids	
Ciclosporin (oral)	
Golimumab	
Infliximab	
Methotrexate	
Surgery	
Tacrolimus	
Tofacitinib	
Vedolizumab	
Vedolizumab and a further course of prednisolone	
Other (please specify)	

13.1.2 ULCERATIVE COLITIS: CORTICOSTEROID DEPENDENT - ON THIOPURINE

	Treatment
1.	
2	
3.	
4.	
5.	

13.2.1 ULCERATIVE COLITIS: CORTICOSTEROID DEPENDENT - NOT ON THIOPURINE

In treating a patient with ulcerative colitis, what treatments (assuming that all of these are available in your centre) would you offer either alone or in combination for someone with moderately severe disease, who responds to steroids, but rapidly relapses when the dose is reduced?

(Please tick all that apply)

	(Flease tick all that apply)
	Thiopurine naïve
5-ASA (aminosalicylate)	
Adalimumab	
Adalimumab plus thiopurine* or methotrexate	
Admit for IV steroids	
Ciclosporin (oral)	
Golimumab	
Golimumab plus thiopurine* or methotrexate	
Infliximab	
Infliximab plus thiopurine* or methotrexate	
Methotrexate	
Surgery	
Tacrolimus	
Thiopurine*	
Tofacitinib	
Vedolizumab	
Vedolizumab and a further course of prednisolone	
Vedolizumab plus thiopurine* or methotrexate	
A further course of steroids and add thiopurine* or methotrexate	
Other (please specify)	
	1

^{*}Assuming TPMT satisfactory

13.2.2 ULCERATIVE COLITIS: CORTICOSTEROID DEPENDENT NOT ON THIOPURINE

	Treatment
1.	
2	
3.	
4.	
5.	

$14.1\ ULCERATIVE\ COLITIS:\ CORTICOSTEROID\ RESISTANCE$ - PATIENT ON THIOPURINE

What factors do you take into account when deciding on a treatment for patients with corticosteroid resistant ulcerative colitis? Please rate the following factors with regards to their importance when deciding on treatment.

Route of administration of medication Cancer risk from drugs	Very mportant	Important	Neutral	Low importance	Not at all important
Route of administration of medication Cancer risk from drugs	inportant			importance	important
medication Cancer risk from drugs					
Cancer risk from drugs					
Disease related risk of cancer					
Patient preference					
Patient age					
Infusion bay or service capacity					
Hospital in-patient bed use					
Cost					
Efficacy					
Effect on fertility/pregnancy					
Previous cancer					
Effect on quality of life					
Co-morbidity					
Potential impact of side effects					
Safety – frequency of side effects					
Safety – severity of drug side effects,					
if rare					
Burden on patient – length of					
treatment, inconvenience etc.					
Effect on patient intimacy					
Your own familiarity with treatment					
option as a clinician					
Availability of a treatment in your					
centre					
Effect on mucosal healing					
Other (please specify)					
Other (please specify)					
Other (please specify)					

14.2 ULCERATIVE COLITIS: CORTICOSTEROID RESISTANCE - PATIENT NOT ON THIOPURINE

What factors do you take into account when deciding on a treatment for patients with corticosteroid resistant ulcerative colitis? Please rate the following factors with regards to their importance when deciding on treatment.

	Very	Important	Neutral	Low	Not at all
	important			importance	important
Route of administration of					
medication					
Cancer risk from drugs					
Disease related risk of cancer					
Patient preference					
Patient age					
Infusion bay or service capacity					
Hospital in-patient bed use					
Cost					
Efficacy					
Effect on fertility/pregnancy					
Previous cancer					
Effect on quality of life					
Co-morbidity					
Potential impact of side effects					
Safety – frequency of side effects					
Safety – severity of drug side effects,					
if rare					
Burden on patient – length of					
treatment, inconvenience etc.					
Effect on patient intimacy					
Your own familiarity with treatment					
option as a clinician					
Availability of a treatment in your					
centre					
Effect on mucosal healing					
Other (please specify)					
Other (please specify)					
Other (please specify)					

15. In general terms, in which situations would you consider referring a patient with corticosteroid resistant ulcerative colitis, of moderate severity, for surgery?

- o Once the patient has been deemed to be resistant to systemic corticosteroids
- o After the patient has tried one biologic and this was unsuccessful
- o After the patient has tried two biologic therapies and this had been unsuccessful
- Only when the patient asks about this
- o Only after using all available medical options
- o I would not consider offering surgery

_	Two data not consider offering surgery
С	At any time
	If you have chosen this option, please indicate what factors would lead to the referral
Э	Other – please specify factors below

16. Which of the following treatment(s) (if any) are NOT AVAILABLE for steroid resistant ulcerative colitis at your centre:

	(Please tick all that apply)
5-ASA (aminosalicylate)	
Adalimumab	
Adalimumab plus thiopurine or methotrexate	
Admit for IV steroids	
Ciclosporin (oral)	
Golimumab	
Golimumab plus thiopurine or methotrexate	
Infliximab	
Infliximab plus thiopurine or methotrexate	
Methotrexate	
Surgery	
Tacrolimus	
Thiopurine	
Tofacitinib	
Vedolizumab	
Vedolizumab and a further course of prednisolone	
Vedolizumab plus thiopurine or methotrexate	
A further course of steroids and add thiopurine or methotrexate	
All of the above treatments are available	

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(ase	Scena	าทาดร —	Section	Н

In this section (questions 17-20), you will be given a scenario and asked to give your treatment choices for patients both on thiopurine, and not on thiopurine. A statement describing the scenario will be at the beginning of each question.

17. ULCERATIVE COLITIS: CORTICOSTEROID RESISTANT

A 45 year old man with known ulcerative colitis for three years has ongoing symptoms despite 4 weeks taking prednisolone 40mg daily, orally. He has a stool frequency of six times per day, with blood and mucus, but normal blood test results (ESR, haemoglobin and CRP). Stool cultures are negative. He is on low dose oral aminosalicylates. He has had no hospital admissions and no other flares in the last 2 years.

Assuming that all of these are available in your centre, which treatment or combination of treatments would you typically suggest?

(Please tick all that apply

	in each column)	
	If the patient	Thiopurine
	already on	naïve
	thiopurine*	
5-ASA (aminosalicylate) – oral or combined oral/topical		
Adalimumab		
Adalimumab plus thiopurine* or methotrexate		
Admit for IV steroids		
Ciclosporin		
Golimumab		
Golimumab plus thiopurine* or methotrexate		
Infliximab		
Infliximab plus thiopurine* or methotrexate		
Methotrexate		
Surgery		
Tacrolimus		
Thiopurine alone*		
Tofacitinib		
Vedolizumab		
Vedolizumab plus thiopurine* or methotrexate		
Other (please specify)		

^{*} Assuming TPMT satisfactory

18. ULCERATIVE COLITIS: CORTICOSTEROID DEPENDENT

A 45 year old man with known ulcerative colitis for three years had a moderately severe flare of his symptoms. Stool cultures are negative. His symptoms respond fully to prednisolone 40mg daily, orally and he reduces the dose by 5mg per day each week. When he reaches 25mg/day, his symptoms recur with a stool frequency of six times per day with blood and mucus but normal blood test results (ESR, haemoglobin and CRP).

Assuming that all of these are available in your centre, which treatment or combination of treatments would you typically suggest?

(Please tick all that apply in each column)

in each column)	
If the patient	Thiopurine
already on	naïve
thiopurine*	
	If the patient already on

^{*} Assuming TPMT satisfactory

19. ULCERATIVE COLITIS: CORTICOSTEROID DEPENDENT – BUT RELAPSE AT LOWER DOSE

A 45 year old man with known ulcerative colitis for three years had a moderately severe flare of his symptoms. Stool cultures are negative. His symptoms respond fully to prednisolone 40mg daily, orally and he reduces the dose by 5mg per day each week. When he reaches 5mg/day, his symptoms recur with a stool frequency of six times per day with blood and mucus but normal blood test results (ESR, haemoglobin and CRP).

Assuming that all of these are available in your centre, which treatment or combination of treatments would you typically suggest?

	(Please tick all
	that apply)
5-ASA (aminosalicylate)	
Adalimumab	
Adalimumab plus thiopurine* or methotrexate	
Admit for IV steroids	
Ciclosporin	
Golimumab	
Golimumab plus thiopurine* or methotrexate	
Infliximab	
Infliximab plus thiopurine* or methotrexate	
Methotrexate	
Surgery	
Tacrolimus	
Thiopurine*	
Tofacitinib	
Vedolizumab	
Vedolizumab and increase prednisolone	
Vedolizumab plus thiopurine* or methotrexate	
Other (please specify)	

^{*} Assuming TPMT satisfactory

20. ULCERATIVE COLITIS: CORTICOSTEROID DEPENDENT – THIOPURINE EXPOSED

A 45 year old man with known ulcerative colitis for three years had a moderately severe flare of his symptoms. He had been on azathioprine at 2mg/kg for 18 months and 6 months before the current flare, his thioguanine nucleotide levels were deemed to be within the target therapeutic range. Stool cultures are negative. His symptoms respond fully to prednisolone 40mg daily, orally and he reduces the dose by 5mg per day each week. When he reaches 5mg/day, his symptoms recur with a stool frequency of six times per day with blood and mucus but normal blood test results (ESR, haemoglobin and CRP).

Assuming that all of these are available in your centre, which treatment or combination of treatments would you typically suggest?

	(Please tick all
	that apply)
Increase the corticosteroids to 40mg per day	
5-ASA (aminosalicylate)	
Adalimumab	
Admit for IV steroids	
Golimumab	
Infliximab	
Methotrexate	
Surgery	
Tacrolimus / ciclosporin	
Tofacitinib	
Vedolizumab	
Other (please specify)	

^{*} Assuming TPMT satisfactory

	Use of Endoscopy – Section F	
maxin	n a person with ulcerative colitis and ongoing symptoms, after what you feel to be a num duration and dose of systemic corticosteroids, do you feel endoscopic assessment to m disease activity is necessary?	
0	Almone	
0	Always Never	
0	Sometimes	
O	If sometimes, what affects this decision:	
	in sometimes, what affects this decision.	
	f endoscopy is deemed necessary, what degree of endoscopic appearance would you as indicative that a change of treatment was required?	
0	Normal or inactive disease;	
0	Mild disease (erythema, decreased vascular pattern, mild friability)	
0	Moderate disease (marked erythema, absent vascular pattern, friability, erosions)	
0	Severe disease (spontaneous bleeding, ulceration)	
0	Any degree of abnormality	
0	Appearances more severe or unchanged from a recent endoscopy	
0 0	Always Never Sometimes If so, what affects this decision	
	f endoscopy is deemed necessary, what degree of endoscopic change would you regard as tive that a change of treatment was required?	
ndica	tive that a change of treatment was required?	
	tive that a change of treatment was required? Normal or inactive disease;	
ndica	tive that a change of treatment was required?	
ndica o o	Normal or inactive disease; Mild disease (erythema, decreased vascular pattern, mild friability)	
ndica	Normal or inactive disease; Mild disease (erythema, decreased vascular pattern, mild friability) Moderate disease (marked erythema, absent vascular pattern, friability, erosions) Severe disease (spontaneous bleeding, ulceration) Any degree of abnormality	
ndica	Normal or inactive disease; Mild disease (erythema, decreased vascular pattern, mild friability) Moderate disease (marked erythema, absent vascular pattern, friability, erosions) Severe disease (spontaneous bleeding, ulceration)	
ndica	Normal or inactive disease; Mild disease (erythema, decreased vascular pattern, mild friability) Moderate disease (marked erythema, absent vascular pattern, friability, erosions) Severe disease (spontaneous bleeding, ulceration) Any degree of abnormality	
ndica	Normal or inactive disease; Mild disease (erythema, decreased vascular pattern, mild friability) Moderate disease (marked erythema, absent vascular pattern, friability, erosions) Severe disease (spontaneous bleeding, ulceration) Any degree of abnormality	
ndica	Normal or inactive disease; Mild disease (erythema, decreased vascular pattern, mild friability) Moderate disease (marked erythema, absent vascular pattern, friability, erosions) Severe disease (spontaneous bleeding, ulceration) Any degree of abnormality Appearances more severe or unchanged from a recent endoscopy use this space to add any additional comments about how you define, and treat,	
ndica	Normal or inactive disease; Mild disease (erythema, decreased vascular pattern, mild friability) Moderate disease (marked erythema, absent vascular pattern, friability, erosions) Severe disease (spontaneous bleeding, ulceration) Any degree of abnormality Appearances more severe or unchanged from a recent endoscopy use this space to add any additional comments about how you define, and treat,	

$\label{lem:project} \begin{tabular}{ll} Project document 2-Semi-structured interview schedule for healthcare professional qualitative interviews \\ \end{tabular}$

Introduction

- Introduce yourself and explain that the purpose of the interview is to understand how they treat patients with ulcerative colitis (UC) which is resistant to steroids, the treatments they offer and decisions they make about, how they made and make decisions about these treatments, which treatments they prefer and why.
- Before the interview begins, check if the participant has any questions, ensure they are still happy to go ahead, and agree to the interview being audio recorded.
- Remind the participant that they can take a break from, or end, the interview at any time.

Context

- 1. Please tell me briefly about your work with people with ulcerative colitis?
 - Job role; time in post; department; caseload; MDT working etc.
 - What does the pathway for patients with UC look like?

Definitions

- 2. How do you understand steroid resistance in UC?
 - What does steroid resistant UC mean to you?
 - How do you know when the steroids have stopped working for patients?
 - Does the timing make a difference?
 - 2 weeks / 4 weeks / another timeframe?
 - Is steroid resistance different to steroid dependence?

Treatment options and preference construction

- 3. Please can you tell me a bit about the treatments you offer/use with UC patients who are resistant to steroids?
 - What are the exceptions to this? How do you need to vary this for patients with different characteristics?
- 4. What treatment options do you typically discuss with patients?
 - What do you think of the options?
- 5. Do you feel fully informed about the available treatment options?
 - Where do you get information about treatments from?
- 6. How do you decide on which treatment(s) to offer?
 - How do you monitor this over time?
- 7. What are the factors that you take into consideration when before offering treatments to your patients?
 - What's the most important thing to you when offering a treatment?

Prompts:

Efficacy;

- *Is it effective?*
- *Is it more effective than other options? (compared to other effective treatments)*
- How quickly does it work? Does a difference between days and weeks matter?
- Nature of the benefit (symptoms, mucosal healing, quality of life)?

Side effects;

What side effects?

- o repeat course of steroids (eg in context of introducing thiopurine or vedolizumab) causes weight gain, changes in appearance, diabetes, affect bone density
- o thiopurine: infection, cancer risk especially in elderly.
- o anti-TNF (adalimumab, golimumab and infliximab) increases infection risk, lymphoma risk
- o vedolizumab: less infection risk
- o tofacitinib: still limited experience. Uncertainty about herpes zoster infection and lipid increase; now emerging caution about thromboembolic risk.
- How severe?
- How common?
- Need for monitoring?

Co-morbidity (including previous cancer); cancer risk of treatments;

- Which drug might you choose? Which cancer might influence your decision?
- Does the fact that some of these drugs need concomitant use of thiopurine immunosuppression make a difference?
- If such combination therapy was not needed, would that influence your decision? Ie reduced thiopurine related side effects including cancer

Cost;

Route of administration; intravenous (hospital attendance); subcutaneous (self-injection required) or oral

Frequency of administration;

Safety;

Patient age;

Patient preference;

Quality of Life;

Extent of professional experience with specific treatment options?

Anything else?

- What's the most important thing to patients when accepting a treatment?
 - i. Prompts: route of administration; frequency of administration; hospital attendance; side effects; efficacy; QoL; anything else?
- 8. What are the factors that you take into consideration before referring a patient for surgery?
 - Why is that? Can you say a little more about that?
 - What kind of information is provided about elective surgical options for UC in your hospital?
- 9. How have your preferences for different treatments changed over time?

Treatment choice

10. I have given you an example case history of someone with steroid resistant UC:

Case scenario (note: this will be on a separate page and sent to participants)

A 45 year old man with known ulcerative colitis for three years has ongoing symptoms despite 4 weeks taking prednisolone 40mg daily, orally.

He has a stool frequency of six times per day, with blood and mucus, but normal blood test results (ESR, haemoglobin and CRP). Stool cultures are negative.

He is on low dose oral aminosalicylates. He is already on thiopurine.

He has had no hospital admissions and no other flares in the last 2 years.

- Do you have any experience of this type of patient?
- In your usual clinical practice, how would you treat this patient?
 - o Prompt: focus on one in particular or discuss in general
 - o How would this change if the patient was not already on thiopurine?
- Do you feel that these patients are typically being managed appropriately?
- In ideal circumstances, how do you think these patients should be managed?

Closing remarks

Is there anything else that you would like to say that you haven't had the chance to say yet?

Project document 3 – Semi-structured interview schedule for patient qualitative interviews

Introduction

- Introduce yourself and explain that the purpose of the interview is to understand their experiences of different treatments for ulcerative colitis (UC), how they made and make decisions about these treatments, which treatments they prefer and why.
- Before the interview begins, check if the participant has any questions, ensure they are still happy to go ahead, and agree to the interview being audio recorded.
- Remind the participant that they can take a break from, or end, the interview at any time.
- Explain to the participant that you are a non-clinical researcher, and recommend that if they have any clinical questions about their treatment, these should be directed to their IBD Nurse or Consultant.

Health condition

- 1. Please tell me about your ulcerative colitis?
 - When were you diagnosed?
 - Did you have any symptoms before diagnosis?
 - Did you have any difficulties getting a diagnosis?
 - What was the diagnosis process like for you?
 - What are your symptoms now?
- 2. How did getting a diagnosis affect you?
 - How did it affect you physically/mentally/socially?
- 3. Did you look for more information about your UC after you were diagnosed?
 - Why do you think that is?
 - Where did you look?
- 4. How do you think that UC will affect you in the future?

Treatment options and preference construction

- 1. Please can you tell me briefly about the main components of the treatment you have had for UC?
 - Can you remember the specific treatments that you have had?
 - Have you had a look at the list of drugs that I sent through?
 - Was surgery discussed as an option?
 - i. If yes, can you tell me about what was discussed?
 - ii. If no, do you know why not?
- 2. How did you decide on which treatment(s) to have?
 - What about steroids?

- How did you know when these had stopped working for you?/ Why do you feel that you came off steroids?
 - i. Symptom control, Side effects, Frequency of treatment, Tapering dose and timing of relapse (earlier/later)
- 3. What treatment options did you discuss?
 - What did you think of the options?
- 4. Did you feel fully informed about your options?
 - (e.g. risks/benefits)
 - Why?
- 5. Did you feel like you had enough support when considering treatment options?
- 6. Did you look for alternatives to the treatments your doctors discussed with you?
- 7. What things about the treatments helped you make a decision on what treatment to have?
 - What's the most important thing to you when choosing a treatment?
 - i. Trust/relationship with HCP, side-effects, route of administration, hospital attendance, frequency of administration, Impact/effectiveness on symptoms.
- 8. How have your preferences for different treatments changed over time?

Treatment choice

- 1. Did you think there were choices to treat your UC after steroids were deemed not to be working?
 - How did you feel about having a choice of treatments?
- 2. Was there an opportunity to be involved in making the decision about your treatment?
- 3. What support did you want when considering treatment options?
 - What support did you want when having treatment?
- 4. Who did you involve in helping you make a decision?
 - Why did you involve these people?

Consolidation

- 1. How do you feel about your choice of treatment(s) now?
 - Did you feel that this was the right choice for you at the time?
 - What is the thing you valued most about your treatment?
 - i. e.g. remission, better quality of life, less pain etc.
 - What is the thing you least liked about your treatment?
 - i. e.g. method of drug administration, hospital attendance, side effects etc.
- 2. Has your life changed since your [specific] treatment?
- 3. Would you change anything about the decisions that you have made about your treatment? Why?

Closing remarks

Is there anything else that you would like to say that you haven't had the chance to say yet?