

Second interview schedule (12 months) for CONSTRUCT participants

Patients will be contacted to arrange a convenient date/time. Explain that this is the second of the interviews they agreed to take part in when they consented to CONSTRUCT, information will be very valuable, help us to understand what happens after treatment and therefore I would like to speak to you uninterrupted for up to one hour.

1st transcript to be read before interview, pertinent things said by patient to be noted and available to aid interview. Will also help with validation of previous interview and understanding of change over time.

Firstly, I want to ask you questions about your health and well-being and then I will ask you questions about the treatment you received. The next questions are about your health and well-being.

1. When I spoke to you 9 months ago, you told me the following things were having an effect on your health or your views about your health. Have those changed in any way, for the better or perhaps for the worse?
2. 9 months ago you told me a range of practical and personal problems relating to UC. Are you aware of any changes that I should know about?
3. Has anything about your quality of life changed since 9 months ago?
(*social, physical, emotional, mental*)

Before we move on to the second part of the interview are there any other comments you would like to make about your health that we have not covered.

I am interested in what has happened treatment-wise over the past 9 months since we last spoke, so the next questions will be about this.

4. Nine months ago you described the treatment you were having as xxxx. What treatment(s) have you had since then?
(*have to hand the date of CONSTRUCT treatment*)
(*A ? Has had more of the drug they were randomised to - infliximab or ciclosporin*)
(*B ? Has had treatment with the drug they were not randomised to*)
(*C ? Had different drug treatments*)
(*D ? pt may have had surgery since last interview*)
5. What are your views about the treatment(s) you have received in the last 9 months?
 - a. What were the positive aspects of the medicines you were given?
 - b. What were the challenging aspects of the medicines you were given
(*+&- about impact on UC*)
(*side effects, treatment lasted or not, ? worth it*)
 - c. Positive and challenging aspects of the way the medicines were administered?
(*+ &- aspects of being given it-convenience, process, impact*)
6. Has there been a change in your daily life compared to 9 months ago
(*Treatment, care, lifestyle, routine?*)

Questions for drug treatment only	Questions for surgery pts
<p><i>If participant has been treated with both infliximab & ciclosporin since randomisation in CONSTRUCT ask:</i></p> <p>7. Which of the medicines/treatments did you prefer and why?</p> <p>a. If had infliximab & ciclosporin – specifically which preferred</p> <p>b. ? because that treatment regime suits your lifestyle?</p> <p>I would now like to ask:</p> <p>8. What do you think of the care you are currently receiving for UC? <i>(trying to find out about access to service/IBD nurses etc)</i></p> <p>9. What is your opinion about the time that it takes you to access that care?</p> <p>10. What has changed in your relationship with doctors and nurses since we last spoke <i>(way communicate or interact)</i></p> <p>a. Is that because</p> <p>i. Change in treatment / drugs?</p> <p>ii. Lack of change in treatment / drugs?</p> <p>iii. ? surgery</p> <p>iv. Better or worse communication with you?</p> <p>v. Something else?</p> <p>b. What has brought about that change or lack of change (in treatment, drugs, surgery, something else)?</p> <p>11. Does bringing up your illness with you again now, through questionnaires and interviews, bother you?</p> <p>CONSTRUCT Pt Interview Schedule RCT V3-0 05Aug2011.doc</p>	<p>7. Thinking back to the drug treatment you had a year ago, what are your views about it now? <i>If have been treated with infliximab & ciclosporin over the year, which did they prefer?</i></p> <p>8. Since your surgery, can you describe what difference the operation has made to your daily life?</p> <p>9. Since the surgery, how has the operation affected your quality of life?</p> <p>10. Have you had a reversal operation since the surgery? If yes, when was that and how are you now? If no, do you anticipate having a reversal?</p> <p>11. Since I last asked, how are you coping with the ileostomy <i>(mentally, emotionally, physically)</i>?</p> <p>a. Has that changed?</p> <p>12. How has it affected your relationships with others?</p> <p>a. Friends & family</p> <p>b. Doctors and nurses and other healthcare professionals</p> <p>13. Do you think you would prefer to be on long term treatment for your ulcerative colitis rather than have had a colectomy? Have your views changed? <i>(Perceptions of safety & implications of having different treatments. Surgery – if last resort why?)</i></p> <p>14. Do you feel the decision to go ahead with the operation was good or bad? Have your views changed since we last spoke?</p> <p>15. Of all the treatments you have had for UC which would you consider as the most successful and why?</p> <p>CONSTRUCT Surgery Pt Interview Schedule V2-0 05Aug2011.doc</p>

I have finished asking the set questions - are there any other comments you would like to make?

NB –remember to thank the participant for taking part in 2 interviews