

## **PROVISIONAL INTERVIEW SCHEDULE** (Version 1.0 20/03/2013)

**Study title: Living with Crohn's Disease: Expectations, Experiences and Decision-Making in Relation to Autologous Stem Cell Treatment**

### **Introduction and thanks**

Confirm participant agrees with the use of the digital recorder. Confirm consent to take part; assure that they are free to withdraw at anytime.

Themes and prompts\*:

#### **1. Patient journey:**

(prompts) To get us started I wonder if you would mind telling me about the story of your condition?  
How did you come to be diagnosed with Crohn's disease?  
What made you think there was something wrong and go to your doctor?  
How did you feel when you found out there was something wrong?  
What was a normal day like for you before your condition started?

#### **2. Perceived impact of CD:**

(prompts) How would you describe what life is like living with Crohn's disease?  
What is life like for you? During times of flare or remission of symptoms?  
What does it mean to you to be a person with your condition?  
What role does your condition play in your life?  
What picture do you have of yourself now?  
What do you know about your condition?  
What information have you had about it?

#### **3. Treatments received for CD (for those who have taken part in ASTIC, focusing predominantly on HSCT):**

(prompts) Please describe your thoughts about the treatments you have received for your Crohn's disease?  
What treatments have you had so far for your CD?  
For example, what are your experiences of - drug treatments (including stem cell treatment for relevant participants), nutritional therapy treatments, surgical treatments?  
How did you come to find out you needed the treatment?  
What was your understanding about the treatment?  
What was your understanding about clinical trials?

#### **4. Expectations of treatment:**

(prompts) Please take me through what you remember about your expectations about the treatment before having it?  
What information did you receive about the treatment before having it?  
How was this provided?  
How did you feel about this part of your care?

**5. Decision-making & risk:**

(prompts) How would you describe your part in the decision-making process about the treatments you have had for your CD?  
How would you describe your feelings about the potential benefits of the treatments?  
How would you describe your feelings about the potential risks of the treatments?

**6. Experiences:**

(prompts) Could you tell me about your experience of your treatment?  
Were there any things that you did that you found helped you most during your treatment?  
How did the treatment meet with your expectations?  
Since having the treatment, how do you feel about it now?  
If you were talking about the treatment to another person with CD, what would you say to them?  
How would you describe your views on taking part in clinical trials that test treatments for people with CD?  
If relevant, please describe your experiences of taking part in clinical trials relating to your CD?

**7. Recommendations:**

(prompts) What recommendations would you have for ensuring other people with CD like yours have the best possible experience?  
What is the best way to provide information about treatments and clinical trials for CD?  
What is the best way of supporting people during the treatment itself?  
How best can we support people before the treatment?  
How best can we support people during the treatment?  
How best can we support people after the treatment is finished?

Is there anything else you would like to say about your experience of living with CD?

**8. Finally,** Would you like me to send you a copy of the research findings?

General probes:

Could you tell me a bit more about that?  
What do you mean by....  
What could have been done differently?  
How did you find that experience?  
How did that make you feel?

\*please note – not all prompts will be asked, they provide a guide to the interviewer as to the potential topic areas should this be required during the interview.