

## INTERVIEW GUIDE

### Title

Optimising the transition from paediatric to adult healthcare of young people with rheumatic diseases: a qualitative study

### Interview Plan

#### Introduction

- Explanation about the study, semi-structure interviews and informed voluntary consent
- Explanation that participants can stop the interview at any time without having to provide a reason.

#### Possible Interview Questions and Prompts

A semi-structured list of predominantly open ended and framed questions (17) will be used to focus the discussion, additionally prompts will be used to help stimulate the conversation.

Interview questions for adolescents and young adults with rheumatic disease.

#### **1. General experiences of living with a rheumatic disease**

- a. How did you feel when you were first told you have a rheumatic disease?
- b. How does living with a rheumatic disease impact your daily activities? (School/study, work life, relationships)
- c. Has your rheumatic disease changed how you feel about yourself? If so how?
- d. What's the hardest thing about having a rheumatic disease; how do you cope with these challenges?
- e. How do you think this rheumatic disease might impact your future?

#### **2. Experiencing transition from paediatric to adult health care**

- a. Have you discussed transition to adult healthcare with your doctor?
- b. What age were you when you discussed transition to adult healthcare with your doctor? When/ What age did you transfer to the adult clinic?
- c. What sorts of things did you discuss or ask your doctor about transitioning to adult healthcare?
- d. How did the process of transition begin? /What are the plans for your transition to adult healthcare? (Did you attend adolescent clinics in the adult hospital? Were you given a contact at the adult hospital? Did both an adult and paediatric doctor provide a consultation)
- e. Did you feel the plan was individualised/unique to your own situation?
- f. Did you find the paediatric and adult rheumatologist communicated well between each other and yourself?
- e. What aspects of transitional care are you most happy or satisfied with at the moment?
- f. What aspects of transitional care are you most unhappy or dissatisfied with?
- g. What sort of information and support did you receive when moving to the adult hospital?
- h. Pre-transition/During: What are you most worried about/ excited about for your transition?

#### **3. Improving transition from paediatric to adult care**

- a. How can doctors, nurses or other people working at the hospital or clinic provide better support for transition from paediatric to adult healthcare?

- b. What sort of information do you think should be available for young people moving to adult healthcare? How could it be given? (doctor, nurses, internet, phone apps, booklets)
- c. Other clinics take a slightly different approach. What are your thoughts on
  - adolescent clinics in adult hospital, adult and paediatric joining in the same consultation, a co-ordinator contact at the hospital

#### **4. Self-management**

- j. How confident do you feel about taking care of your own health and organising your clinical appointments? Why?
- k. What sort of things do you do to maintain your health? (*Medicine, diet, rest/activity*)

#### **5. Social support (dealing with challenges of independence – work, school life, exams etc.)**

- a. Do you feel you have someone who supports you? How do they help you? (organising appointments, driving you to appointments)
- b. How have your parents/guardian coped with your transition to adult healthcare?
- c. How do they let you gain independence in determining your healthcare?
- d. Who knows you have a rheumatic disease? (friends, relatives, school, work, etc...) How do they treat you?
- e. Do you know anyone else with a rheumatic disease? Are they a similar age? Are they also transitioning to adult healthcare?
- f. Have you joined a support group? Why/why not? (face to face, online)
- g. What sorts of initiatives, support, help is needed to improve the experiences of young people with rheumatic disease undergoing transition to adult healthcare?
- h. Have you ever found your location to be a barrier in accessing your healthcare?

#### **4. Closing**

- a. Is there anything else you would like add that you think might be useful for us to know?

### **Interview questions for parents and carers of young people with rheumatic disease**

#### **1. General experiences of caring for a young person with a rheumatic disease**

- a. How did you feel when you were first told your child/dependent had a rheumatic disease?
- b. How does caring for a young person with a rheumatic disease impact your daily activities? (work, finances)
- c. How does caring for a young person with a rheumatic disease impact your relationships? (partner, other children, friends, work colleagues)
- d. Has caring for a young person with a rheumatic disease changed how you feel about yourself? If so how?
- e. How do you think caring for a young person with a rheumatic disease might impact your future?

#### **2. Transition from paediatric to adult health care and self-management**

- a. Have you discussed transition to adult healthcare with the doctor? How old was your child?
- b. What sorts of things did you discuss about transitioning to adult healthcare?
- c. What are the plans for transition to adult healthcare? (Are you taking a less active role in the care of your young person with a rheumatic disease? Are they attending an adolescent clinic in the adult hospital? Were you given a contact at the adult hospital? Did both an adult and paediatric doctor provide a consultation)
- d. How were you helping your young person through their transition?

- Are you participating in all the clinical appointments for your young person with a rheumatic disease?
- Are you organising the clinical appointments
- filling scripts?
- e. What aspects of transitional care are you most happy or satisfied with at the moment?
- f. What aspects of transitional care are you most unhappy or dissatisfied with?
- h. What sort of information and support did you receive when moving to the adult hospital?
- j. How confident do you feel about your young person taking care of their own health and organising their clinical appointments? Why?
- k. What sort of things do you do to help your young person maintain their health during this time? (*Medicine, diet, rest/activity*)
- l. What sort of things are you worried about for your young person moving to adult healthcare?
- m. What sort of things are you looking forward to?

### **3. Improving transition from paediatric to adult care**

- a. How can doctors, nurses or other people working at the hospital or clinic provide better support for parents and caregivers for transition from paediatric to adult healthcare?
- b. What sort of information do you think should be available for parents and caregivers about transition to adult healthcare? How could it be given? (doctor, nurses, internet, phone apps, booklets)

### **4. Social support (dealing with challenges of your young persons new independence – work, school life, exams etc.)**

- a. Do you feel you have someone who supports you? How do they help you? (emotional support, help finding further employment)
- b. How do you help your young person cope with the transition to adult healthcare?
- c. How are you letting them gain independence in their healthcare?
- d. Who knows your child has a rheumatic disease? (friends, relatives, school, work, etc...) How do they treat you?
- e. Do you know any other parents with a rheumatic disease?
- f. Have you joined a support group? Why/why not? (face to face, online)
- g. What sorts of initiatives, support, help is needed to improve the experiences of parents and caregivers of young people with rheumatic disease undergoing transition to adult healthcare?
- h. Did you receive much support financially? Have you had any troubles financially with your child's treatment?
- i. Have you ever found your location to be a barrier in accessing your child's care?

### **5. Closing**

- a. Is there anything else you would like add that you think might be useful for us to know?