Supplementary materials

Appendix 1. All interview guides

Interview guide adolescents (16-18 years old)

- 1. What are your thoughts on the provided care up till now?
- 2. What measures do you take when you have MO related complaints?
 - a. Do you know when to call the hospital?
 - b. Do you make the call for an appointment yourself?
- 3. Soon you will become eighteen years old, do you know what that means for your healthcare?
 - a. When you become eighteen you will transfer to the adult care, what are your thoughts about that?
 - b. Are you ready for transfer?
 - i. What made you ready?
 - ii. What do you need to be ready?
 - iii. Are there any bottlenecks for transition?
 - c. Do you worry?
- 4. What are your thoughts on the separate locations of the paediatric care and adult care?

Interview guide young adults (18-25 years old)

- 1. What are your thoughts on the provided care up till now?
- 2. How did you experience the transfer of paediatric care to adult care?
 - a. What made you ready?
 - b. What did you need to be ready?
 - c. Were there any bottlenecks for transition?
 - d. Did you worry?
- 3. What measures do you take when you have MO related complaints?
 - a. Do you know when to call the hospital?
 - b. Do you make the call for an appointment yourself?
- 4. What are your thoughts on the separate locations of the paediatric care and adult care?

Interview guide parents of adolescents

- 1. What are your thoughts on the provided care up till now?
- 2. What measures does your child take when they have MO related complaints?
 - a. Does he/she know when to call the hospital?
 - b. Does he/she make their own appointments?
- 3. Soon your child will become eighteen years old, do you know what that means for their

healthcare?

- a. What are your thoughts on the upcoming transfer of your child?
- b. Do you think your child is ready?
 - i. What made him/her ready?
 - ii. What does he/she need according to you to become ready?
 - iii. Are there any bottlenecks for transition?
- c. Do you / your child worry?
- 4. What are your thoughts on the separate locations of the paediatric care and adult care?

Interview guide parents of young adults

- 1. What are your thoughts on the provided care up till now?
- 2. What measures does your child take when they have MO related complaints?
 - a. Does he/she know when to call the hospital?
 - b. Does he/she make their own appointments?
- 3. How did you experience the transfer of paediatric care to adult care?
 - a. Was your child ready for transfer?
 - i. What made him/her ready?
 - ii. What did he/she need to be ready?
 - iii. Were there any bottlenecks?
 - b. Did you worry?
- 4. What are your thoughts on the separate locations of the paediatric care and adult care?

Interview guide health care providers

- 1. What are your thoughts on the transitional care?
- 2. What are the preparations for transfer?
 - a. What could be better organized in the transitional care?
 - b. Are there any bottlenecks?
 - c. What is the ideal transitional care?
- 3. What is your role in transitional care? What are/should be the roles of other healthcare

providers?

4. What part should parents take in the transitional care?

Appendix 2. A-priori themes

A-priori themes that were formed using the available literature on transitional processes in other

chronic diseases:

- 1. Expectations and beliefs on transitional care.
- 2. Shift in roles between adolescent and his parents.
- 3. Timing of transfer.
- 4. Cultural gap between adult and paediatric services.
- 5. Need for better information.
- 6. Recommendations for the transitional process.

Appendix 3. On your own feet Transfer Experience scale

Subscale A: Alliance between paediatric and adult care			
Mean		Questions	
(SD)	Agree %		
3.850		I can manage well on my own during hospital consultations, also	
(0.9333)	85	without my parents	
3.650		I have confidence in my adult health care providers	
(0.9333)	70		
3.850		I am happy with the care I receive in the adult care setting	
(0.8127)	85		
3.4		My new care provider was well informed about me and my	
(1.1877)	65	condition	
3.350		I was taken care of very well in the adult care setting	
(1.1821)	60		
3.3		Treatment recommendations in the adult care setting are similar	
(1.1286)	50	to those I used to receive in paediatric care	
2.9		There was good collaboration between paediatric and adult care	
(1.0712)	25		
2.950		The way of working and dealings with patients in adult care are	
(1.0990)	35	similar to what I was used to in paediatric care	
2.9		When I first met my adult care provider, I knew exactly what was	
(1.1192)	30	expected of me and what I could expect from him / her	
2.6		I don't really experience many differences between paediatric	
(1.2312)	25	and adult care	
2.250		Before the transfer I had already met my new health care	
(1.0195	15	providers	

Subscale B: Preparation for transfer				
3.550		The transfer to adult care was announced timely and did not		
(1.0990)	60	come as a surprise		
3.6		My parents were ready to transfer to adult care		
(1.0954)	55			
3.150		I was ready to transfer to adult care		
(1.4244)	45			
3.1		The timing of the transfer was just about right		
(1.3727)	50			
2.850		I was well prepared for the transfer to adult care		
(1.3485)	30			
2.850		I received enough information about the transfer to adult care		
(1.2680)	30			
2.2		I had a say in the timing of the transfer		
(0.9515)	5			