Supplementary File 1.
Interview guide for a young person pre-transition

Background questions

- What year did you have your SCI?
- Which hospital did you go to?
- How long were you in hospital?
- What paediatric/children’s support services do you access?

Main questions

- What does healthcare transition mean to you?
- Do you know other young people with SCI that have moved from children’s support services to adult support services? What have they told you about the process of transition? What did they feel about their experience? Was it good, bad, were they excited, scared?
- Now thinking ahead to when you turn 18 and move from the children’s support services to adult support services. What are your thoughts about this? How does this make you feel? (scared, excited, indifferent)
  - What are you looking forward to?
  - What would make it difficult to move?
  - What concerns or fears do you have about the move?
  - What would your contact with healthcare look like leading up to transfer? After?
  - How could others (doctors parents etc) help you to get ready for the move? Where do you think you could find information on supporting the move from children’s to adult services?
  - What do you think you’ll see when you get to the adult hospital?
  - What things are you planning to do to get ready for the move?
  - What do you think would make the move easier for you?
- Imagine you could plan your ideal move: What would it look like?
  - What information would you like to know?
  - What resources would you like to have? Examples: prompt to give the some ideas… Would hearing about other young people’s experiences be helpful?

Ending questions
Is there anything else that you think is important to tell me that would help us to understand your needs?
Interview guide for a young person post-transition

Background questions

- What year did you have your SCI?
- Which hospital did you go to?
- How long were you in hospital?
- What paediatric/children’s support services do you access?

Main questions

- What does healthcare transition mean to you?
- Now thinking back to when you turned 18 and moved from the children’s hospital to your current adult hospital. Could you tell me a little about how this happened for you? How did you feel?
  - Were you looking forward to it?
  - What made it easy to move?
  - What made it difficult to move?
  - What concerns or fears did you have about the move?
  - What was your contact with healthcare like leading up to transfer?
    - After?
  - How did others (doctors, parents, etc.) help you to get ready for the move? What did you do to get yourself ready?
  - How could others (doctors, parents, etc.) have helped you to get ready for the move? What could you have done to get yourself ready?
  - Could you describe if you had any expectations of adult care?
  - What would have made it easier?
  - What they did well?
- If you could change one thing about your move from the children’s hospital to your current hospital, what would it have been? What would you have changed?
- Imagine you could have helped plan your move. What would it have looked like?
  - What information would you have liked to have known?
  - What resources would you have liked to have had at the time?
  - Do you think hearing about other young people’s experiences would have been helpful?

Ending questions

Is there anything else that you think is important to tell me that would help us to understand your needs?
Interview guide for a parent/caregiver pre-transition

Background questions

- What year did your son/daughter sustain their SCI?
- Which hospital did they go to?
- How long were they in hospital?
- What paediatric/children’s support services do you/they access?

Main questions

- What does healthcare transition mean to you?
- Now thinking ahead to when your son/daughter turns 18 and moves from children’s to adult healthcare services. What are your thoughts about this? How does this make you feel? (scared, excited, indifferent)
  - What are you looking forward to?
  - What would make it difficult to move?
  - What concerns or fears do you have about the move?
  - What would your contact with healthcare look like leading up to transfer? After?
  - How could others (doctors parents etc) help you to get ready for the move? Where do you think you could find information on supporting the move from children’s to adult services?
  - What do you think would make the move easier for you?
- How do you think your son/daughter is feeling about the move?
  - What are his/her concerns or fears?
  - What do you think would make the move easier for them?
- Imagine you could plan your ideal move: What would it look like?
  - What information would you like to know?
  - What resources would you like to have? Examples: prompt to give them some ideas... Would hearing about other young people’s or their caregivers’ experiences be helpful?

If time permits

- Thinking about managing your child’s healthcare, what do you think your role or responsibility is? What is your child’s?
- How do you imagine your role and responsibilities will change when your son/daughter turns 18?
  - How does this make you feel? How do you think your son/daughter may feel? (scared, excited, indifferent)
  - What would make it difficult?
  - What concerns or fears do you have?
  - What would you tell your son/daughter about managing their healthcare on their own?
How could others (doctors, parents, etc) help you to get ready for
the change in role/responsibilities?

What things are you planning to do to get ready for the change?

What do you think would make the change easier for you? For your
child?

Ending questions
Is there anything else that you think is important to tell me that would help us to
understand your needs? Your son/daughter’s needs?
Interview guide for a parent/caregiver post-transition

Background questions

• What year did your son/daughter sustain their SCI?
• Which hospital did they go to?
• How long were they in hospital?
• What paediatric/children’s support services do you/they access?

Main questions

• What does healthcare transition mean to you?
• Thinking back to when your son/daughter turned 18 and moved from the children’s to their current adult hospital/healthcare services. Could you tell me a little about how this happened for you? How did you feel?
  o Were you looking forward to it?
  o What made it easy to move?
  o What made it difficult to move?
  o What concerns or fears did you have about the move?
  o What was your contact with healthcare like leading up to transfer? After?
  o How did others (doctors parents etc) help you to get ready for the move? What did you do to get yourself ready?
  o How could others (doctors parents etc) have helped you to get ready for the move? What could you have done to get yourself ready?
  o Could you describe if you had any expectations of adult care? Were these met?
  o If you could change one thing about your move from the children’s hospital to your current hospital, what would it have been? What would you have changed?
• How do you think your son/daughter managed the move?
  o Did they have any concerns or fears?
  o What do you think could have made it easier for them?
• Imagine your ideal move. What would that process have looked like?
  o What information would you have liked to have known?
  o What resources would you have liked to have had at the time? Examples: prompt to give the some ideas... Do you think hearing about other young people’s experiences or their caregivers’ would have been helpful?

If time permits

Thinking about managing your child’s healthcare, how do you think your role or responsibility has changed since they turned 18?
(If changed)

• What responsibilities has your child taken over from you?
If you had to tell someone else about how to manage or cope with switching responsibilities in managing their child’s healthcare, what would you tell them?

What did you tell your son/daughter in preparation for taking over responsibility for managing their healthcare on their own? Is there anything you wish you had told them?

How could others (doctors, parents, etc) have helped you or your child to get ready for the change in role/responsibilities?

(If their role hasn’t changed)

Is there a reason why your role/responsibilities have stayed the same?

Would you like it to change and how so?

What concerns or fears do you have?

How could others (doctors, parents, etc) help you or your child get ready for the change in role/responsibilities?

Ending questions

Is there anything else that you think is important to tell me that would help us to understand your needs? Your son/daughter’s needs?