**The Structured Narrative and Imagery Based Intervention Delivered by a Social Robot (SNIBI-R) Script**

**Participant Number:\_XXXXX\_**

0.1 Hello. Thank you for participating in the SNIBI study. To move on to the next question at any time during this conversation, just push the green button on my left foot or say ‘next’. If you want me to repeat a question, just push the red button on my right foot or say ‘back’. Sometimes when I am listening, I make a beeping noise. If you would like me to stop making these noises, just say ‘quiet’ or gently tap the top of my head, then just use the buttons on my feet to go to the next question or back to hear the question again.

**Session 1**

**Introduction (Ending at 00:02)**

**Baseline Survey = 30 minutes (00:32)**

1. **New Skill** = **13 minutes (00:45)**
   1. Okay, to get started, can you tell me about something that you have achieved recently, something that may have been somewhat difficult for you, but you overcame that difficulty, and that helped you feel better about yourself?

It doesn’t have to be something major, it could be something simple like learning a new game, figuring out a puzzle, solving a problem around your house. It can be anything, but try and pick something that you feel, at least, a little bit proud of.

* 1. So, what were some of the things you did to get ready for this achievement?
  2. Did anyone else help you to achieve this?
  3. What part did they play?
  4. Did anything get in your way or make it difficult to achieve this?
  5. Why was it important to you that you overcame these difficulties?
  6. When it got difficult, what helped you to stick with it?
  7. What do all of these things say about the things that are important to you?
  8. What do all of these things say about your values? Values can be things like: humility, respect, kindness, honesty, loyalty, courage, perseverance, self-discipline, leadership, compassion, generosity, and dependability. Do any of these values relate to this experience of learning a new skill?
  9. Can you think of some other values related to this experience that are not on this list?
  10. What could be some good things that could happen to you if you used these values in other parts of your life?
  11. What might other people notice about you if these values were a bigger part of your daily life?
  12. How have these values helped you in the past with cystic fibrosis?
  13. How do you think they can help you with CF in the future?

Thank you so much for sharing this with me. Now, if it is okay with you, I’d like to show you a brief video of a teenager, named Angela, talking about how she’s dealing with CF.

[Show Video on an ipad] = **7 minutes (00:52)**

1. **Video Reaction = 8 minutes (00:60)**
   1. As you listened to Angela’s story, what did you hear that stood out to you?

[If long pause (15 sec?):] What struck a chord with you? What were you drawn to in her story?

* 1. Angela talked about holding on to her dream of becoming a dancer. Do you have any dreams or goals like that, either big or small?
  2. Pretend you were Angela’s friend or sibling. If Angela was getting discouraged by her CF, what would you want to tell her to help her feel better and stay on track wither her goal?
  3. What are some things that you are doing to keep the CF from getting in the way of following your dreams?
  4. Angela said that, even though the CF usually has to be really important, she didn’t want to let the CF take over her life. She said she is committed to becoming a dancer and she is not going to let CF stop her from doing that. Is there anything else you could do to help you follow your goals?

**Session 2[Fun Activity with Andy] = 5 minutes (00:05)**

**[Recap of Session 1] = 2 minutes (00:07)**

Welcome back to the SNIBI study. Just as a reminder, if you want to move on to the next question, just push the green button on my left foot or say ‘next’. If you want me to repeat a question, just push the red button on my right foot or say ‘back’. Sometimes when I am listening, I make a beeping noise. If you would like me to stop making these noises, just say ‘quiet’ or gently tap the top of my head, then just use the buttons on my feet to go to the next question or back to hear the question again.

1. **Reflecting on one image from home:**  **= 4 minutes (00:11)**
2. Did you bring any images or objects that are helpful to you? If so, can you show me one? If not, can you tell me about an image or an object that is helpful to you?
3. What makes this special to you?
4. When you look at this, how does it make you feel?
5. How does this help you through difficult situations?

Landscape of Action:

1. **Past: = 10 minutes (00:18)**

Can you try and remember a day or a moment where you didn’t have many problems or you didn’t feel like you had many problems? If you can’t think of a specific moment it, try to imagine yourself in a place where you don’t have many problems. You may want to try closing your eyes to imagine yourself in that time and place. Imagine it as though you are really there. [PAUSE]

1. Now, can you tell me about that time?
2. What do you see around you?
3. What do you hear, smell, feel, touch?
4. Who is there with you?
5. What was it about that time that made it better?
6. **Present:** **= 7 minutes (00:25)**
   1. Is there anything about that moment that could help you now?
   2. Is there anything about that moment that could help you to cope with CF?
   3. Are there things people can do to make a difficult situation more like that moment?
   4. What helps keep you from worrying about CF or having to go to the hospital?
7. **Preferred Future: = 8 minutes (00:33)**
   1. If you imagine yourself a few years from now and you’re doing everything you can to keep CF from being such a big problem, what would you be doing?
   2. Are there some aspects of your life where CF gets in the way where it doesn’t really have to, like sleepovers or keeping CF a secret?
   3. Is there anything else you want to move from the “life with CF” category to the “life outside of CF” category?
   4. What are some steps between where you are now to where you want to be?
   5. What else can help you get to the next step?
   6. Is there anything else that could help keep you from worrying about CF or having to go to the hospital?

Landscape of Meaning:

1. **Meaning: =** **3 minutes (00:36)**
   1. Sometimes, people who have had to face some big challenges like CF say that there are some upsides to it. What upsides have you seen?
   2. Sometimes people say having a big challenge like CF gives them different priorities. Some things become more important to them that may not be so important to someone who hasn’t had to face such a big challenge. What have you found?
   3. Tell me about any ways you feel CF has made you stronger, braver, or closer to other people?
   4. Do you feel there is some meaning or purpose that has come out of your struggle with CF?
   5. Are the thoughts you have about how you are coping with CF helpful to you? What can you do to help make these thoughts more helpful?
2. **Position/ Stance:** = **4 minutes (00:40)**
3. When you are faced with your CF, and all that comes with it, is there anything you want do differently?
4. Is there anything else you would like to commit to in order to make your life with CF better?
5. If someone doesn’t understand or agree with these commitments, how will you explain it to them in a respectful way?
6. **Strategy/ Approach:** **=** **3 minutes (00:43)**
7. What are some steps you can take to make progress towards these commitments?
8. How can the values that we’ve discussed help you make progress towards these commitments?
9. How can the people in your life help you make progress towards these commitments?
10. **Audience: = 4 minutes (00:47)**
    1. Who are the people that believe in you and believe that you can get to a better place with your CF?
    2. What do these people see in you that leads them to believe in you?
    3. What would you like others to know about you and how you are dealing with CF?
    4. Is there anything these people can do to help you not to worry about CF or worry less?
11. **Identity:** **= 4 minutes (00:51)**
12. Who is your favourite hero?
13. What makes them a hero?
14. Who would you most like to be like and why?
15. **Values:** **3 minutes (00:54)**
16. In your struggle with CF, what are the most important things in your life right now? How can these things help you with CF?
17. What has your CF taught you?
18. **Identifying Symbols:** **= 4 minutes (00:62)**
19. When you think about all of the things that help get you through difficult situations (e.g. images, objects, toys, artworks, pets, special places), how do these things help you?
20. Do these things remind you of anything?
21. Why do they bring you comfort?
22. **Creating Imagery to contain worry activity: = 8 minutes (00:70)**

We are almost done with this session, there is just one more activity I’d like to do with you if that is okay? So, as you know, CF is a serious condition, and it is normal with such a serious condition that there will be times you will feel worried about the CF or upcoming treatments. When thoughts of worry come up, no matter how real the thing is that we are worried about, in the end, the worry is just a thought.

Worried thoughts are a bit like clouds, there will be times where they will come and block out the sunlight. It’s pointless and unnecessary to try and control these thoughts, but you can treat them like clouds, letting them have their own space and time and you can take comfort in the knowledge that they will also pass you by. It can also be helpful to recognize, when you are in the shadows of those clouds of worry, that the sunlight is still there and it can still shine through those clouds and bring you warmth and comfort. The sunlight in this example is all of the things you have been telling me about these past two sessions. The sunlight is the values, skills, supports, commitments, and the meaning that you have taken from this situation. By staying focused on these things when thoughts of worry come up, the worry has less power and casts less of a shadow over your life. Would you like to imagine what that would be like?

If you are comfortable, can you close your eyes and imagine yourself a year from now. Now imagine you have a new treatment for your CF coming up in a few days, one that you have never had before, but one that has a lot of potential to make a big difference in your life and to give you a lot more freedom. The only problem is that the treatment is rather nasty and difficult. As you are thinking about this treatment coming up, you start to think about all of the things that could possibly go wrong. The worrying keeps getting worse, your heart keeps beating faster, and your thoughts are racing, but then you say to yourself, “hold on a second, these thoughts of worry are just that, thoughts! These thoughts don’t have any power over me and they don’t determine how I respond to a situation.”

If your eyes are still closed, keep them closed, if not, try closing them again. Now the worry thoughts are still there, you’re just putting them in their place, which is a place where they can’t harm you. If there are any particular worries you have, or if it is just worry in general, just imagine those worries are in a bubble and you are letting that bubble float up to the sky. If it’s helpful for you, you can name some of those worries. Or you may see the bubbles as taking on a certain shape or appearance that is meaningful to you. If so, you may want to describe what these bubbles look like to you, or you can keep it to yourself. The important thing is that you are imagining those bubbles floating up and away and disappearing into a cloud full of other worries. Now that those worried thoughts are contained within that cloud, you are choosing to let that cloud float on by and you are focusing on the warm sunlight that is still right there. It is currently behind the cloud, but it will soon come out again.

1. **Summarize: = 5 minutes (00:60)**

Thank you so much for sharing all of that with me! I know there’s so much more to your story than what we have discussed and I know we are not going to be able to cover it all, but never forget that you are always the author of this story and you are always in the process of writing this amazing story.

1. Is there anything else we should include in this story that we haven’t discussed yet?
2. What do you think the title of this story should be (you may want to relate it to what it would look like on the other side of this struggle)?
3. Is there anything we discussed that we should leave out of this story?

**Session 3 – Definitional Ceremony**

**[Participant will share the robot with the audience] = 10 minutes (00:10)**

[The study staff member will address the participant and the participant’s chosen audience – family, friends, and/or caregivers.] **= 5 minutes (00:15)**

In the past two times that we met, [Participant] has been telling me about his journey with Cystic Fibrosis (CF). Since then, we have put together a book about [Participant]’s journey and now he would like to share this story with you as you are all an important part of this journey. This book is just a rough draft version of [Participant]’s story. The final version will be a hard cover version and [Participant] may or may not wish to include some of the thoughts and reflection that are made by the people in this room. It’s important that we all keep in mind that this is [Participant]’s story and this story book is for him. Please do not be offended if your amazingly insightful comments do not make it into the final version of this story. Also keep in mind that everything that is said in this room is being recorded, but it will only be used for [Participant]’s story.

[Participant], it’s up to you, would you like to read this story to your audience, or would you like me to read it? The idea behind what we are doing today is that, when people struggle with a chronic illness like CF, it is common for them to feel as though this disorder defines them and writes their stories. One of the main goals of this study is to help [Participant] to feel as though HE is in charge of his life and HE is the author of his story. While it is important to recognize the impact and the significance of CF in [Participant]’s life, it doesn’t need to define who he is. Our hope is that this intervention will help [Participant] to be in a place where he is continuing to define and re-define who he is in the face of CF.

That said, [Participant] has recognized you all as being very important characters in his story. The point of this session is to begin, or to improve upon, a process where [Participant] is able to comfortably share his story with you and others, as well as to hear and draw strength from your reflections upon his story. So [Participant] is going to read his story to us, and then you will all have a chance to reflect upon this story. The purpose of this reflection process isn’t so much about applauding or cheerleading or giving advice and your opinion, rather it is about reflecting upon this story which may be different than what you may already know or think you know about [Participant]. So while you are listening to this story, think about some of the themes that you notice, what it says to you about life and humanity, what you were drawn to, what you related to, and/or how you were touched by this story. The point of this exercise is to, wherever [Participant] may have felt like his life was ‘degraded’ by the disorder, you get to help him now ‘re-grade’ his life. Are there any questions? Should we listen to [Participant]’s story now?...

[Read Story] **= 15 minutes (00:30)**

[After the story has been read] Thank you so much for sharing your story with us. [Participant], now we are going to talk to your audience about how they were impacted by your story. If you miss anything they say here, don’t worry, everything is being recorded and what is said here will be emailed to you and you will get a chance to re-write your story and include anything that is said today. [Participant], is it okay with you if your audience takes a look at your book while we are discussing it?

1. **Audience Reflections = 10 minutes (00:40)**

As you listened to [Participant]’s story, what did you hear that stood out to you? What struck a chord with you? What were you drawn to in his story?

What were some particular words or expressions that caught your attention?

What did [Participant]’s story tell you about what might be important to him?

* 1. Did you get the impression from this story that [Participant] is committed to keeping the CF from getting in the way of following his dreams or goals? If so, how would you describe these commitments?
  2. As [Participant] grows in these commitments, what might it make more possible for him, or what doors might it open for him?
  3. How can you support him in his commitment to not let the CF get in the way of his dreams or goals?
  4. In the future, if [Participant] gets discouraged and feels as though the CF is taking over his life, what can you do to help him renew these commitments?

[These same audience questions will be emailed to the participant so he can have the opportunity to reflect upon his audience’s comments and rewrite his story to include these reflections if he wishes.]

1. **Closing = 5 minutes (00:45)**

Thank you all for participating in this conversation and engaging with [Participant]’s amazing story. As you know, this story we discussed today is just a small part of [Participant]’s story and he is going to continue to re-author this story and author new stories. It is our hope that the conversation today is just one small piece of an ongoing conversation that is open and supportive to [Participant]’s desire to define his life both in relation to CF and outside of CF. Sometimes, because everyone wants what’s best for [Participant], yet there can be different opinions about what the “best” is, it can be difficult to have this conversation.

It may be helpful to have someone who is outside of this conversation there to help keep this open and supportive conversation going. A counsellor may be helpful for this as they are trained to facilitate these kinds of conversations. If you are interested in contacting a counsellor, but you are not sure how, please contact a nurse or feel free to contact a study staff person even after the study is complete at:

Jeremy Russell, PhD Student | Ph: 07 3069 7552 | Email: [j21.russell@hdr.qut.edu.au](mailto:j21.russell@hdr.qut.edu.au)

**Brief Survey (HADS) = 10 minutes (00:55)**

**Qualitative Interview (20 min):**

[Questions to be asked at week 4, after participant and parent have completed the T3 survey and after they have been given the final, hardcover storybook. Questions will be addressed to the participant first and then to the parent (if present)].

There is one more survey to do in 4 weeks, but apart from that, you are now all done with the study activities. Thank you so much for your time and participation in this study! If it is okay with you, can I ask you a few questions about how this study went for you? Your answers to these questions will help us to understand what about this study might be helpful for young people with CF. These questions help us get an in-depth and personal response to the study. Please be really honest in your answers, even about things you didn’t like or things that have gotten worse. Don’t worry about hurting our feelings.

*[Use nonspecific follow-up questions for each question—e.g. Anything else…? What else…? Are there any other things…? If a previous answer covers a later one, only ask about other things.]* Tell me about your experience of being in this program.

1. What were the best things about this program? *[Wait for answers before asking about specific areas]*
   1. …sessions?
   2. …robot?
   3. …story book?
2. What wasn’t so good about this program? *[Wait for answers before asking about specific areas]*
   1. …sessions?
   2. …robot?
   3. …story book?
3. What things did you learn during the program?
   1. What did you learn about yourself?
4. The next questions ask about any changes from when you started the study to now. If I ask you about something that is the same or worse than when you started the study, please tell me about it. It is really helpful for me to know about those things as well.
   1. Did this program help you to cope with CF?

[If needed] In what way?

* 1. Did the program help you to deal with worry?

[If needed] Tell me about that.

* 1. Are you getting on better with your friends, parents, or others?

[If needed] In what ways?

* 1. Do you feel more comfortable talking to others about CF?

[If needed] Tell me about that.

* 1. Is there anything about CF that really bugged you before that doesn’t bug you as much now?

[If needed] What’s that?

* 1. Is there anything that CF kept you from doing before that’s not such a problem now?

[If needed] What’s that?

* 1. Do you feel like you have a new sense of meaning or purpose in life? [If needed] Can you tell me about that?

1. Are there any *(other)* ways this program could be improved, so it was more helpful for young people with CF? [If yes] How?

**Intervention to Storybook Rubric:** [How well does the Storybook reflect the most important elements of the intervention?]

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | A. Past | B. Present | C. Future | D. Meaning Making | E. Stance |
| 0 | Not Mentioned | Not Mentioned | Not Mentioned | Not Mentioned | Not Mentioned |
| 1 | One item is moderately described, yet some key items are still missing OR multiple items are mentioned but not described OR the items don’t really fit into a plotline. | One item is moderately described, yet some key items are still missing OR multiple items are mentioned but not described OR the items don’t really fit into a plotline. | One item is moderately described, yet some key items are still missing OR multiple items are mentioned but not described OR the items don’t really fit into a plotline. | One item is moderately described, yet some key items are still missing OR multiple items are mentioned but not described OR the items don’t connect to the plotline. | One item is moderately described, yet some key items are still missing OR it is not clear why the stand is being taken OR the strategy is not connected to a desired future. |
| 2 | Past events, skills developed, and/or coping strategies are well represented and linked through time forming a plotline. Either one item is described well or multiple items are described moderately well. | Current events, skills, and/or coping strategies are well represented and linked through time forming a plotline. Either one item is described well or multiple items are described moderately well. | Desired future events, skills, and/or coping strategies are well represented and linked through time forming a plotline. Either one item is described well or multiple items are described moderately well. | Meaning, Identity, and Values are well represented and are derived from the plotline developed in A, B, and C. Either one item is described well or multiple items are described moderately well. | The stand the participant is taking to not be defined by CF and/or the strategy to reach the desired future is well represented. Either one item is described well or multiple items are described moderately well. |
| Score: |  |  |  |  |  |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | F. Social Supports | G. Externalisation | H. Metacognition | I. Mental Imagery | J. Audience Reflections |
| 0 | Not Mentioned | Not Mentioned | Not Mentioned | Not Mentioned | Not Mentioned |
| 1 | Only one person is mentioned and reengaged OR multiple people are mentioned but not reengaged. | CF and subsequent problems are described well yet not in neutral terms OR not described well but neutral | One item is moderately described, yet some key items are still missing OR multiple items are mentioned but not described | An image is described yet not very vivid OR the image is not likely to be easy to recreate during future worries | One item is moderately described, yet some key items are still missing OR multiple items are mentioned but not described well |
| 2 | People are identified who have helped with life with CF and/or develop life outside of CF. Reengagement with these people for the participant’s current coping, desired future, or a role they play has changed or been added. | The nature and the quality of the problem of CF, and how it leads to subsequent problems, is described well but in neutral terms – not totally negative, not wrestled with, or as a problem to be resolved or reformed. | Internal cognitions regarding the control, monitoring, or appraisal of negative thoughts, emotions, or worry are well described. | A positive, adaptive image of the participant responding well to worry in the future, or an image from the past where the participant is free from worry, is vivid and appears easy for participant to recreate during future worries | A rich description of what the audience was drawn to, images that were evoked, personal resonance, and/or how they were moved by the story. |
| Score: |  |  |  |  |  |

**Total = \_\_\_\_\_\_\_\_\_**