

This document includes the following materials:

### **Data Collection Instructions – for Intensive Planning and Support Coordinators (IPSCs)**

*Pages 2-3*

- This section explains what the IPSCs (also designated as Support Person) need to follow to collect information for the study. It provides a clear order of tasks – from checking if a DSP Participant can join the study, conducting informed consent, supporting study participants to complete the survey, and finishing with background questions.
- These steps ensure that data collection is done in a consistent, respectful, and ethical way.

### **Survey | Section 1: Quality of Life – for Study Participants, supported by IPSCs**

*Pages 4-9*

- This section contains the main survey questions about the Participant's quality of life. The questions are written in plain language, with adapted response scales, to make sure they are accessible and easy to answer for people with different disabilities. These answers will be used to understand how quality of life changes during the move from institutional to community living.
- IPSCs should support Study Participants to complete the survey by reading and explaining any question necessary.
- The final two questions in this section are open-ended and give Participants a chance to describe for themselves, how they are feeling about the move, and their life in general, if they want to. If possible, please support the Study Participants with this section by transcribing their words, or inviting them to write or draw themselves. There is a space for a caption at the bottom of the text box, for you or the Study Participant to add context to their drawing or words, if applicable.

### **Survey | Section 2: About the Participant – for IPSCs**

*Pages 10-13*

- This section collects background information to help explain the Participant's situation. Questions cover sociodemographic questions about the Study Participant, their living arrangements, and their level of support. This information helps the Research Team interpret the quality of life results and understand the context of each participant's experience.

### **Survey | Section 3: About the Transition Process – for IPSCs**

*Pages 14-15*

- This section includes questions about the transition process of the Study Participants.
- At the end of this section, there is a **Feedback Box** – a dedicated space for IPSCs to leave any feedback on the survey and their data collection experience (e.g., lengthiness of the survey, adequacy of the language).

### **Supporting Materials | Alternative Survey Questions for Section 1 Examples**

*Page 16*

- This material helps to provide alternative ways to frame each question in Section 1 to prompt and support answers.

## Data Collection Instructions for IPSCs

The following steps will guide you through the data collection process for this study.

- Please complete each step in order. Move to the next step only after fully finishing the one before it. This ensures that DSP Participants are treated respectfully, the study is carried out ethically, and the information collected is accurate and consistent.
- Completing all the steps should take between 25 to 35 minutes. If needed, you and your DSP Participant may complete Step 1 and the remaining Steps (from 2 to 5) in different moments.

### Step 1. Explain the Study and Obtain Informed Consent

- Review the Informed Consent Form with the DSP Participant. Please, ensure you have a dedicated time (between 10 to 20 minutes) and space that supports a calm environment to go through the Informed Consent Form with the DSP Participants.
- **Make sure the DSP Participant understands:** what the study is about, that taking part in the study is their choice, and that they can stop participating at any time.
- **When it appears that a DSP Participant lacks the capacity to make a decision** about their participation in the study, the IPSC must not approach, recruit, or enroll them in the study.
- **If the DSP Participant agrees to take part in the study**, collect the signatures.
- Both copies of the **Informed Consent Signature Page need to be signed** – one is to be submitted to the Research Team and another is to stay with the Study Participant.

### Step 2.A. Conduct the Section 1 | *Quality of Life Questions* – For IPSCs and Participants

- Bring a printed copy of this survey when meeting the Participant.
- List the **roles** (NOT the names) of those, other than you and the participant, who are present in the room during the survey interaction.
  - There is space to do so **at the top of each page in Sections 2 & 3**. This helps us better understand how participant's responses may or may not be impacted by their environment.
- Guide the participant through each question. Read out loud clearly and slowly. Provide plain language explanations and show the visuals on the rating scales (i.e., smiley faces or star ranking).
- Should you need alternative wordings for questions or examples, you can find a supporting table at the end of the survey document.
- Allow time for answers, do not rush. Record answers exactly as given. All questions are optional.

### Step 2.B. Complete Section 2 and 3 | *About the Participant and their Transition* – For IPSCs only

- Using your access to the Integrated Case Management (ICM) and Collaborative Case Management (CCM) systems, please respond to the questions about the participant, and their transition process and status.
- Add any additional thoughts or perspectives about the survey and/or your data collection experience in the Feedback Box.
- **Review all answers** from all 3 survey sections; if you need help, remember that you can ask your IPSC Team Lead for support.

### Step 3. Scan Documents

Using the scanners at **your DSP office**, scan the following documents to your DSP laptop:

- Long-form Text Box Answers (Pages 7 and 8) Questions 11 and 13) from this survey
- Any signature pages of supporting consent documentation (Informed Consent, Consent Follow-up, or Withdrawal Form – as needed)

All pages that need to be scanned are indicated by the following icon:



### Step 4. Upload to NS Forms

- To submit the documents, please upload them to the NS Forms survey.
- The following documents should be uploaded into the NS Forms:
  - The previously scanned **IPSC version of the Signature Pages** (in Informed Consent or Consent Follow-up) **or Withdrawal Form**
  - The previously scanned **Long-form Text Box Answers**
  - **All Survey Section Answers** by transcribing the paper information into the digital survey

### Step 5. Email QoL Research Team

- Email the research team at [DSP-QOL@novascotia.ca](mailto:DSP-QOL@novascotia.ca) to confirm your submission to NS Forms.
- Identify in the email subject what you are submitting according to the following:
  - **If consent is provided** - Email Subject: "Survey ID: ####"
  - **If consent is NOT provided** - Email Subject: "Consent Rejection"
    - Please also mention how many consent rejection forms you are uploading, if there are multiple.
  - **If withdrawal is requested:** Email Subject: "Withdrawal"
    - Please also mention how many withdraw forms you are uploading, if there are multiple.
- **Note:** Do not use any personal information in these emails, **refer only to the survey ID.**
- Wait for research team to confirm receipt before moving to step 6.

### Step 6. Shred Paper & Delete All Digital Copies

- Shred all paper copies with personal information at your DSP office, including:
  - **The full paper survey**
  - **Paper versions of Signature Pages or Withdrawal Form**
  - **Any other documents containing personal information**
- If you cannot destroy these documents as promptly as possible you should secure them in a folder physically near you, and in a secure location, such as your DSP office.
- Delete all digital copies from **your DSP laptops Recycle Bin** so that digital copies are permanently deleted, including:
  - **Scanned IPSC version of the Signature Pages or Withdrawal Form**
  - **Scanned Long-form Text Box Answers**

**Thank you for your time and availability in supporting the DSP Quality of Life Study.**

**Survey | Section 1: *Quality of Life – for Study Participants, supported by IPSCs***

These questions are about understanding how you feel right now. You can take as long as you want and there are no right or wrong answers! To respond, add a **X** by the answer that best describes how you feel.

**Participant CCM Identifier:** \_\_\_\_\_ **Date:** \_\_\_\_ (DD) \_\_\_\_ (MM) \_\_\_\_ (YYYY)

**1. How good is your life these days?** (select the one that applies)

Very Good	★★★★★	
Good	★★★★☆	
Okay	★★★☆☆	
Bad	★★☆☆☆	
Very Bad	★☆☆☆☆	

**2. How important are the things you do in your life?** (select the one that applies)

Very Important	★★★★★	
Important	★★★★☆	
Okay	★★★☆☆	
Not Important	★★☆☆☆	
Not Important at All	★☆☆☆☆	

**3. How happy did you feel yesterday?** (select the one that applies)



**Dark Green**



**Light Green**



**Yellow**



**Orange**



**Red**

Very Happy	Happy	Okay	Sad	Very Sad

**Participant CCM Identifier:** \_\_\_\_\_ **Date:** \_\_\_\_ (DD) \_\_\_\_ (MM) \_\_\_\_ (YYYY)

**4. How worried did you feel yesterday?** (select the one that applies)



**Dark Green**



**Light Green**



**Yellow**



**Orange**



**Red**

Very Calm	Calm	Okay	Worried	Very Worried

**5. How do you feel with your family, friends, or people close to you?** (select the one that applies)



**Dark Green**



**Light Green**



**Yellow**



**Orange**



**Red**






Very Happy	Happy	Okay	Sad	Very Sad

**6. Do you feel welcome by the people around you and where you live?** (select the one that applies)






Very Welcome	★★★★★	
Welcome	★★★★☆	
In Between	★★★☆☆	
Not Welcome	★★☆☆☆	
Not Welcome at All	★☆☆☆☆	

**Participant CCM Identifier:** \_\_\_\_\_ **Date:** \_\_\_\_ (DD) \_\_\_\_ (MM) \_\_\_\_ (YYYY)






**7. Do you feel safe where you live and spend time?** (select the one that applies)

Very Safe		
Safe		
In Between		
Not Safe		
Not Safe at All		

**8. How much control do you have over your own life?** (select the one that applies)

Complete Control		
A Lot of Control		
Some Control		
A Little Control		
No Control		

**9. How much say do you have about what you do each day?** (select the one that applies)

Complete Choice		
A Lot of Choice		
Some Choice		
A Little Choice		
No Choice		

Participant CCM Identifier: \_\_\_\_\_ Date: \_\_ (DD) \_\_ (MM) \_\_\_\_ (YYYY)

10. How do you feel about your future, like having what you need and feeling safe?  
(select the one that applies)

				
Dark Green	Light Green	Yellow	Orange	Red
Very Good	Good	Okay	Bad	Very Bad

11. How are you feeling about where you live right now?  
With the help of your Support Person, you can write or draw your answer in the box below:



Caption for the words/drawing above (optional):

Participant CCM Identifier: \_\_\_\_\_ Date: \_\_ (DD) \_\_ (MM) \_\_\_\_ (YYYY)

12. How do you feel about the move to a new place to live? (select the one that applies)

				
Dark Green	Light Green	Yellow	Orange	Red
Very Good	Good	Okay	Bad	Very Bad

13. Is there anything else you want to share about how you feel?  
With the help of your Support Person, you can write or draw your answer in the box below:



Caption for the words/drawing above (optional):



**End of survey. Thank you for taking the time to answer those questions!**

***ISPC's to please continue to the following page to complete some final questions.***

**Participant CCM Identifier:** \_\_\_\_\_ **Date:** \_\_\_\_ (DD) \_\_\_\_ (MM) \_\_\_\_ (YYYY)

**Who else was/is in the room, while the participant completed the survey:**

\_\_\_\_\_  
(please list their role/job title, and NOT their name)

## Survey | Section 2: About the Participant – for IPSC to complete

These questions will help us understand more about the participants. All responses will not be identifiable, ensuring privacy for both you and the participants.

**14. What type of disability does this participant have?** (select with an **X** all that apply)

Physical Disability	Intellectual Disability	Long-term Mental Illness

**15. What level of support does this participant currently receive?** (select with an **X** the one that applies)

Level 1 – Minimal	Level 2 – Moderate	Level 3 – High	Level 4 – Enriched	Level 5 – Intensive

**16. What facility type is or was the participant living in prior to transition?**

<b>A Residential Care Facility (RCF)</b>		(select if applies)
<b>An Adult Residential Centre (ARC)</b>		(select if applies)
<b>A Regional Rehabilitation Centre (RRC)</b>		(select if applies)
<b>A Developmental Residence (DR)</b>		(select if applies)
<b>A Group Home (GH)</b>		(select if applies)

**Participant CCM Identifier:** \_\_\_\_\_ **Date:** \_\_\_\_ (DD) \_\_\_\_ (MM) \_\_\_\_ (YYYY)

**Who else was/is in the room, while the participant completed the survey:**

\_\_\_\_\_  
(please list their role/job title, and NOT their name)

**17. What region is or was the participant living in prior to transition?**

<b>Central</b> (Counties: Halifax, Hants)		(select if applies)
<b>Eastern</b> (Counties: Antigonish, Guysborough, Cape Breton Regional, Inverness, Richmond, Victoria)		(select if applies)
<b>Northern</b> (Counties: Colchester, Cumberland, Pictou)		(select if applies)
<b>Western</b> (Counties: Annapolis, Kings, Digby, Yarmouth, Shelburne, Queens, Lunenburg)		(select if applies)
<b>I don't know</b>		(select if applies)
<b>Prefer not to say</b>		(select if applies)

**18. What is the age of this participant?**

<b>16-19</b>	<b>20-24</b>	<b>25-29</b>	<b>30-34</b>	<b>35-39</b>
<b>40-44</b>	<b>45-49</b>	<b>50-54</b>	<b>55-59</b>	<b>60-64</b>
<b>65-69</b>	<b>70-74</b>	<b>75-79</b>	<b>80-84</b>	<b>85-89</b>
<b>90+</b>	<b>I don't know</b>	<b>Prefer not to say</b>		

**19. What year did this participant first start receiving support from a DSP care facility?**

<b>Year:</b>	
<b>I don't know</b>	(select if applies)
<b>Prefer not to say</b>	(select if applies)

**Participant CCM Identifier:** \_\_\_\_\_ **Date:** \_\_\_\_ (DD) \_\_\_\_ (MM) \_\_\_\_ (YYYY)

**Who else was/is in the room, while the participant completed the survey:**

\_\_\_\_\_  
(please list their role/job title, and NOT their name)

**20. What is the participant's legal gender?** (select with an **X** the one that applies)

<b>Female</b>	
<b>Male</b>	
<b>Other/X</b>	
<b>Prefers Not to Report</b>	
<b>Unknown (Did not ask)</b>	

**21. How does this participant describe their race?** (select with an **X** all that apply)

<b>First Nations, Métis or Inuk (Inuit)</b>	
<b>White</b>	
<b>South Asian (e.g., Indian, Pakistani, Sri Lankan)</b>	
<b>Chinese</b>	
<b>Black</b>	
<b>Filipino</b>	
<b>Arab</b>	
<b>Latin American</b>	
<b>Southeast Asian (e.g., Vietnamese, Cambodian, Laotian, Thai)</b>	
<b>West Asian (e.g., Iranian, Afghan)</b>	
<b>Korean</b>	
<b>Japanese</b>	
<b>Prefer not to say</b>	
<b>Other (please specify)</b>	

**21.A. Does this participant identifies with any Indigenous identity?** (select with an **X** all that apply)

<b>First Nations</b>	
<b>Metis</b>	
<b>Inuk/Inuit</b>	
<b>Prefer not to disclose</b>	
<b>I identify with another Indigenous identity (please specify)</b>	
<b>N/A</b>	

**Participant CCM Identifier:** \_\_\_\_\_ **Date:** \_\_\_\_ (DD) \_\_\_\_ (MM) \_\_\_\_ (YYYY)

**Who else was/is in the room, while the participant completed the survey:**

\_\_\_\_\_  
(please list their role/job title, and NOT their name)

**21.B. Does this participant identifies with any local Identity?** (select with an **X** all that apply)

<b>Acadian</b>	
<b>African Nova Scotian</b>	
<b>Mi'kmaq</b>	
<b>Gaelic</b>	
<b>Prefer not to disclose</b>	
<b>N/A</b>	

**Participant CCM Identifier:** \_\_\_\_\_ **Date:** \_\_\_\_ (DD) \_\_\_\_ (MM) \_\_\_\_ (YYYY)

**Who else was/is in the room, while the participant completed the survey:**

\_\_\_\_\_  
(please list their role/job title, and NOT their name)

**Survey | Section 3: About the Transition Process – for IPSCs**

**22. Has the IPSC assigned to this participant changed at all throughout their transition process?**

<b>Yes</b>		(select if applies)
<b>No</b>		(select if applies)
<b>I don't know</b>		(select if applies)

**22.A. If you answered “Yes” to the previous question, what date did the IPSC assignment change?**  
(note: an exact date is preferable but not required)

<b>Date:</b>		
<b>I don't know</b>		(select if applies)
<b>Not Applicable</b>		(select if applies)

**23. Has the participant transitioned to community living (i.e., is out of the care facility and living in community)?**

<b>Yes</b>		(select if applies)
<b>No</b>		(select if applies)
<b>I don't know</b>		(select if applies)

**23.A. If you answered “Yes” to question 23, what date was the transition to community living?**

(note: an exact date is preferable but not required)

<b>Date:</b>		
<b>I don't know</b>		(select if applies)
<b>Not Applicable</b>		(select if applies)

**Participant CCM Identifier:** \_\_\_\_\_ **Date:** \_\_\_\_ (DD) \_\_\_\_ (MM) \_\_\_\_ (YYYY)

**Who else was/is in the room, while the participant completed the survey:**

\_\_\_\_\_  
*(please list their role/job title, and NOT their name)*

**23.B. If you answered “Yes” to question 23, what region of Nova Scotia is the participant living in after transitioning?**

<b>Central</b> (Counties: Halifax, Hants)		(select if applies)
<b>Eastern</b> (Counties: Antigonish, Guysborough, Cape Breton Regional, Inverness, Richmond, Victoria)		(select if applies)
<b>Northern</b> (Counties: Colchester, Cumberland, Pictou)		(select if applies)
<b>Western</b> (Counties: Annapolis, Kings, Digby, Yarmouth, Shelburne, Queens, Lunenburg)		(select if applies)
<b>Prefer not to say</b>		(select if applies)
<b>Other</b> (please specify, e.g., relocated out of province)		

**23.C. If you answered “No” to question 23, but have a planned transition date, please provide below.**  
 (note: an exact date is preferable but not required)

<b>Date:</b>		
<b>I don’t know</b>		(select if applies)
<b>Not Applicable</b>		(select if applies)

**24. Please, use this Feedback Box to leave any notes and feedback about the survey and/or your experience on data collection** (e.g., lengthiness of the survey, adequacy of the language etc.).

## Supporting Materials | Alternative Survey Questions for Section 1 Examples

Survey Question	Things you could mention:
<b>1. How good is your life these days?</b>	<ul style="list-style-type: none"> <li>▪ Have you had more good days than bad recently?</li> <li>▪ Did something make you feel happy or proud in the last week?</li> </ul>
<b>2. How important are the things you do in your life?</b>	<ul style="list-style-type: none"> <li>▪ Do you enjoy what you do every day?</li> <li>▪ Are there activities that make you feel good or proud, like spending time with others or helping out?</li> </ul>
<b>3. How happy did you feel yesterday?</b>	<ul style="list-style-type: none"> <li>▪ Were there moments when you felt relaxed or content?</li> </ul>
<b>4. How worried did you feel yesterday?</b>	<ul style="list-style-type: none"> <li>• Did anything make you feel anxious or worried?</li> <li>▪ Did anything make you feel concerned, nervous, uneasy?</li> </ul>
<b>5. How do you feel with your family, friends, or people close to you?</b>	<ul style="list-style-type: none"> <li>▪ Do you feel cared for or understood by the people around you?</li> <li>▪ Are you comfortable talking to them about your thoughts or feelings?</li> </ul>
<b>6. Do you feel welcome by the people around you and where you live?</b>	<ul style="list-style-type: none"> <li>▪ Do people greet you or make you feel included?</li> <li>▪ Do you feel like you belong when you're out and about in your community?</li> <li>▪ Do the people and make you happy and supported?</li> <li>▪ Do you like where you live?</li> </ul>
<b>7. Do you feel safe where you live and spend time?</b>	<ul style="list-style-type: none"> <li>▪ Do you feel safe in your home or in your neighborhood?</li> <li>▪ Do you feel comfortable and protected?</li> </ul>
<b>8. How much control do you have over your own life?</b>	<ul style="list-style-type: none"> <li>▪ Can you make decisions about what happens to you?</li> <li>▪ Do you choose things like what time to wake up or what to do during the day?</li> </ul>
<b>9. How much say do you have about what you do each day?</b>	<ul style="list-style-type: none"> <li>▪ Do you decide your daily activities, like when to eat or rest?</li> <li>▪ Are there things you want to do that you can make happen?</li> </ul>
<b>10. How do you feel about your future, like having what you need and feeling safe?</b>	<ul style="list-style-type: none"> <li>▪ Do you feel confident that you'll have the support you need in the future?</li> </ul>
<b>12. How do you feel about the move to a new place to live?</b>	<ul style="list-style-type: none"> <li>▪ Do you feel unsure or anxious about what will be different in your new place?</li> <li>▪ Do you feel happy or worried about leaving your current home and moving to a new place?</li> <li>▪ Are there things you are looking forward to in your new home, like having more freedom or meeting new people?</li> </ul>

*Feel free to tear this page away from the rest of the document to aid you.*