NOVA SCOTIA

Quality of Life Research Study

Study Roles and Responsibilities Training Material

Disability Support Program

April 30th 2026

Training Session Agenda

DSP Quality of Life Research Study

Table of Contents

- **DSP Research Study** | Understanding the Role of IPSCs
- **Research Study Updates** | Driven from the Ethics submission process
- **First Data Collection Moment** | How to Conduct the Data Collection
- **All Subsequent Data Collection Moments** | How Subsequent Data Collections Differ
- **Study Participant Wants to Stop Participating** | Withdrawal Process
- **After Collecting Data** | Post-Data Collection Process
- **Roles and Responsibilities Overview**
- **Q&A (time-permitting)**

Research Study Overview

DSP QoL Research Study

Refresher: What is this Research Study About?

This research study is about understanding the **impacts of deinstitutionalization** (i.e., moving from care institutions to community living) on the **quality of life (QoL)** of people with disabilities, supported by the Disability Support Program (DSP).

What is My Role as an IPSC?

You have an important role in helping DSP participants throughout their transition journey. IPSCs are there to support and help DSP participants make informed decisions, and this responsibility **extends to this research study**.

This resource aims explains the overview of the study. This session will inform you about the the roles and responsibilities that you will take on to help support this research study, which can be broadly understood as the **4 following steps**:

1. Obtain Informed Consent
2. Conduct Survey
3. Scan Documents
4. Upload to NS Forms
5. Email QoL Research Team
6. Shred Paper Documents

The process remains the same!

To be done in your DSP office

Research Study Updates

DSP QoL Research Study

There are **3 updates and consequent changes** to the DSP QoL Research Study driven form the Ethics submission process. The updates that should be made aware moving are:

1. **DSP participants are no longer required to sign the Withdrawal Form** to drop-out of the study (it is now optional to have the participant signature)
2. **Printed versions of the tools and materials have been made**; photos have been added to this presentation to show how they would look in hand
3. **The NS Forms platform has been developed**; photos have been added to this presentation to show what the form looks like when trying to access it for the first time.

Update to the Withdrawal Form

Research Study Updates

DSP Participant Signature Changes

Before:

- Previously the **Withdrawal Form** required the DSP participants to provide their signatures or a mark to indicate that the were withdrawing from the research study.

Now:

- **Participant signature/mark** on the **Withdrawal Form** is **now optional** – making this process easier and less demanding for the participant.
- Instead**, only the IPSCs signature is mandatory** to ensure that the withdrawal process is well documented.

Apart from this change, the **withdrawal process remains the same**.

*This slide deck has been **updated** to reflect this for when you refer back to it.*

Withdrawal Form – DSP Participant Version

A withdrawal form is a short document your DSP Support Person will use to record your decision of **no longer wanting to take part in the study**. Its purpose is only to let the research team know that you wish to stop taking part in the study and no longer want to be invited to respond to the survey.

You can keep a copy of this Withdrawal Form for yourself, as a record of your decision to stop participating in this study.

Your DSP Support Person will sign this Form to register your decision. You can also sign this Form, if you wish to. Your signature is completely optional and your request to stop participating will be register whether or not you decide to sign this Form.

By completing this form, your DSP Support Person (your IPSC) is making a record that you want to **withdraw** from the DSP Quality of Life research study. This means that:

(a) You will no longer be a part of this study,
(b) You will no longer be invited to respond to the survey, and
(c) Your personal information and support level information will no longer be provided to the research team (Davis Pier).

Withdrawal Confirmation

☐ Yes – I (the participant) want to withdraw from the study and no longer respond to the survey

Name of Participant: _____
(in BLOCK CAPITALS)

Participant Signature (optional): _____
Date: ___ (DD) ___ (MM) _____ (YYYY)

Collaborative Case Management (CCM) Identifier: _____

Name of Person Obtaining Consent (IPSC): _____
(in BLOCK CAPITALS)

IPSC Signature (mandatory):_____

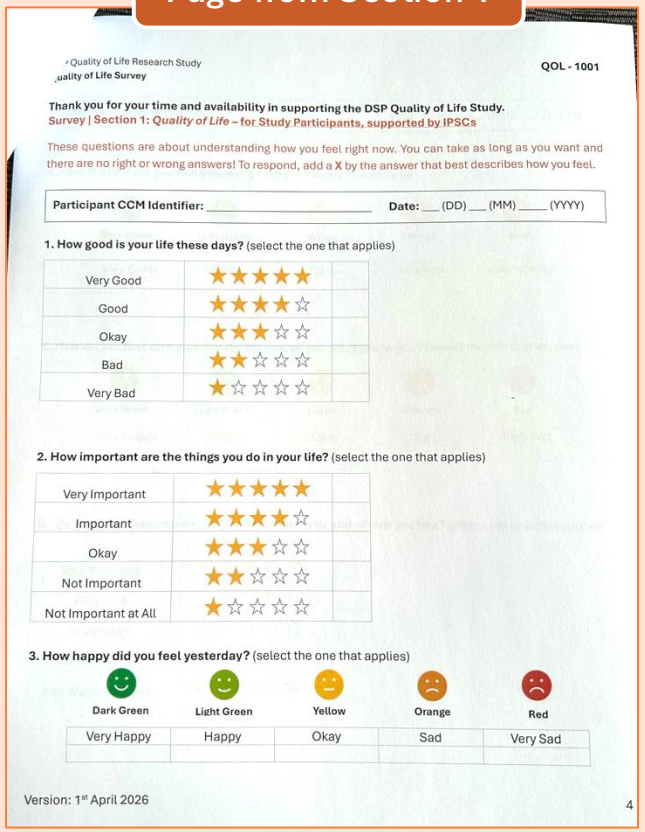
Date: ___ (DD) ___ (MM) _____ (YYYY)

Printed Versions

Research Study Updates

There are now printed versions of the documentation in this slide deck.
Below are examples of the printed materials you will receive to help conduct the survey.

Page from Section 1



Quality of Life Research Study
Quality of Life Survey

QOL - 1001

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	★☆☆☆☆

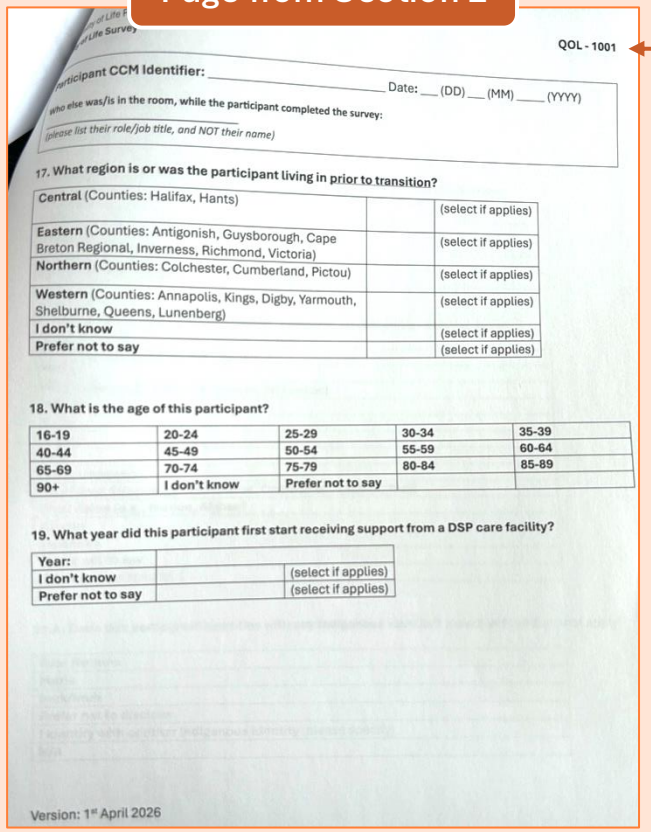
3. How happy did you feel yesterday? (select the one that applies)

Dark Green	Light Green	Yellow	Orange	Red
Very Happy	Happy	Okay	Sad	Very Sad

Version: 1st April 2026

4

Page from Section 2



QOL - 1001

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?

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

18. What is the age of this participant?

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

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

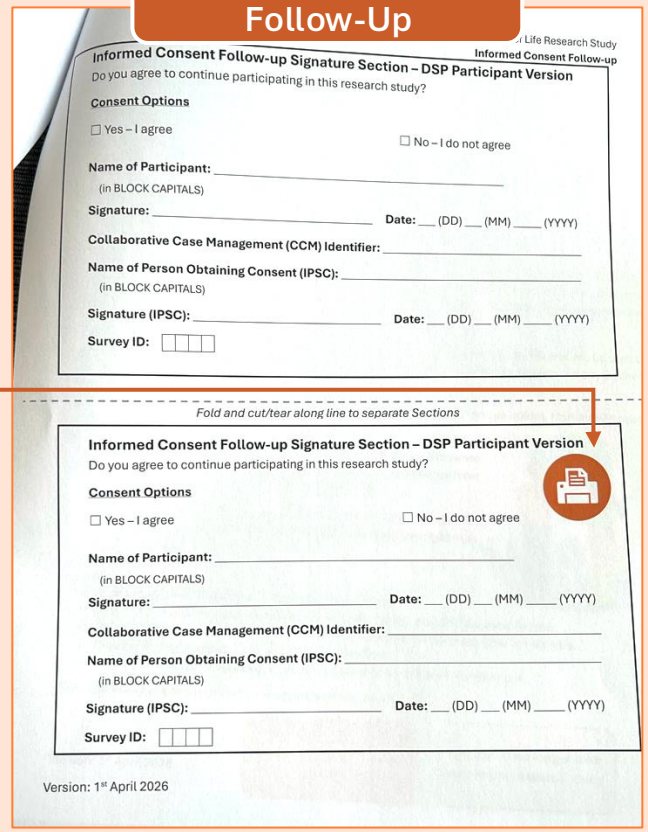
Year:		
I don't know		(select if applies)
Prefer not to say		(select if applies)

Version: 1st April 2026

In the top right-hand corner of the pages in the survey, you can see the **survey ID number** QOL-1001.

You can also see the **printer icon** for which pages must be scanned.

Informed Consent Follow-Up



Quality of Life Research Study
Informed Consent Follow-up

Informed Consent Follow-up Signature Section – DSP Participant Version
Do you agree to continue participating in this research study?

Consent Options

☐ Yes – I agree ☐ No – I do not agree

Name of Participant: _____
(in BLOCK CAPITALS)

Signature: _____ **Date:** ___ (DD) ___ (MM) ____ (YYYY)

Collaborative Case Management (CCM) Identifier: _____

Name of Person Obtaining Consent (IPSC): _____
(in BLOCK CAPITALS)

Signature (IPSC): _____ **Date:** ___ (DD) ___ (MM) ____ (YYYY)

Survey ID: ☐☐☐☐

Fold and cut/tear along line to separate Sections

Informed Consent Follow-up Signature Section – DSP Participant Version
Do you agree to continue participating in this research study?

Consent Options

☐ Yes – I agree ☐ No – I do not agree

Name of Participant: _____
(in BLOCK CAPITALS)

Signature: _____ **Date:** ___ (DD) ___ (MM) ____ (YYYY)

Collaborative Case Management (CCM) Identifier: _____

Name of Person Obtaining Consent (IPSC): _____
(in BLOCK CAPITALS)

Signature (IPSC): _____ **Date:** ___ (DD) ___ (MM) ____ (YYYY)

Survey ID: ☐☐☐☐

Version: 1st April 2026

NS Forms Platform

Research Study Updates

This is the landing page for the research study's NS Forms.
You will receive the link to the NS Forms in email communications from the research team.

NS Forms Intro

DSP Quality of Life Form

Introduction

Thank you for being a part of the DSP Quality of Life Research Study! If you need any help during the uploading process, please reach out to your IPSC Team Lead or contact the research team at DSP-QOL@novascotia.ca.

Checklist

Before you begin this Form, **please check you have all the materials with you:**

1. A **scanned** copy of the IPSC version of one of the following consent documents (please scan these documents before proceeding with this Form):
   - Informed Consent Form **Signature Page**
   - Informed Consent Follow-up **Signature Section**
   - **Withdrawal Form** (if the participant is withdrawing from the study)
2. The paper copies of all the sections in the complete survey:
   - Section 1: Quality of Life (completed with the DSP participant)
   - Section 2: About the Participant
   - Section 3: About the Transition Process
3. A **scanned** copy of pages 7 and 8 of the survey, which include the open-ended responses to questions 11 and 13 of the survey (please scan these documents before proceeding with this Form)

Confirm Scanned Documents

NS Forms Survey Section 1

DSP Quality of Life Form

Section 1: Quality of Life

This page covers the section of the survey that was completed *with* the DSP participant. The questions are written to reflect the exact questions as they are seen in the physical copies, as if written to the DSP participant.

Therefore, **the answers to the questions in this section** should reflect the **exact** answers provided by the DSP participants during your earlier interaction— any exceptions to this will be stated in the relevant questions.

1. How good is your life these days?

- ◯ **Very Good**
- ◯ **Good**
- ◯ **Okay**
- ◯ **Bad**
- ◯ **Very Bad**
- ◯ **Participant did not answer**

2. How important are the things you do in your life?

- ◯ **Very Important**

NS Forms Platform

Research Study Updates

The NS Forms for this study is designed to be almost identical to the physical version — the only difference is that the forms also needs to collect metadata about the survey interaction, including things such as:

- Whether the DSP participant provided consent or not, with the proof of the consent documentation
- The 4-digit survey ID
- The data which the survey was conducted

Survey Details Form Page

DSP Quality of Life Form

Survey Details

I. Did the DSP participant provide consent to participate, or continue participating in this research study? *

If you respond no, you will be prompted to upload proof of the Informed Consent Form Signature Page with a clearly marked "No – I do not agree", or the Withdrawal Form. If yes, you will be prompted to upload proof of the Informed Consent Form Signature Page with a clearly marked "Yes – I do agree" or Informed Consent Follow-up Signature Section.

- ◯ **Yes**
- ◯ **No**

II. Proof of Consent/ Rejection/ Withdrawal of Consent Form Upload

Accepted file types: doc, docx, jpg, jpeg, pdf, png, xls, xlsx. Maximum file size: 20MB.

Drag and drop file here to upload, or

Browse files to select from your computer

End of Form Page

DSP Quality of Life Form

End of Form

Before you finish this form, please confirm that:

1. You will **delete the scanned documents from your DSP laptop now**, including deleting these files from the Trash/ Bin.
2. You will **shred all paper versions of the study materials with personal information as soon as possible** using the shredders that can be found in DSP offices, this includes:
   - The IPSC version of the Signature Page/ Section or Withdrawal Form
   - Section 1: Quality of Life (completed with the DSP participant)
   - Section 2: About the Participant
   - Section 3: About the Transition Process

You may keep pages 1 to 3 of the survey which includes the data collection instructions for IPSCs for future use, as long as they don't have any personal information on them (e.g., notes).

☐ **I am confirming that all scanned pages have been successfully uploaded to this survey and have been deleted, or will be deleted immediately, from my DSP laptop.**

☐ **I am confirming that I will, or have already, shred all paper versions of the study materials that hold sensitive information as soon as possible.**

Study Timeline: Roles and Responsibilities

DSP QoL Research Study

Any questions you would like to discuss together?

Participant living in a care facility

We are **here**

Data collection happening on average every ~6 months

First data collection roles:

- Conduct informed consent with study participant using the **Informed Consent Form**
- Conduct **Survey Section 1** with study participant (if consenting)
- Collect information for **Survey Sections 2 & 3** using CCM/ ICM records
- **Review and submit to NS Forms**

Transition

Participant moves out and starts settling into community living

First post-transition data collection to happen within **~1 or 2 months after moving out**

Data collection **continues** with an **average of every ~6 months**

Review and Submit to NS Forms: Documents will need to be digitized/ scanned after <u>each</u> data collection

Study Timeline: Roles and Responsibilities

DSP QoL Research Study

Any questions you would like to discuss together?

Participant living in a care facility

We are **here**

Data collection happening on average every ~6 months

Transition

Participant moves out and starts settling into community living

First post-transition data collection to happen within **~1 or 2 months after moving out**

Data collection **continues** with an **average of every ~6 months**

Subsequent data collection moments:

- Collect reconfirmation of informed consent with study participant using the **Informed Consent Follow-up**
- **Repeat steps from first data collection:**
  - Section 1 with study participant (if consenting)
  - Section 2 & 3 using CCM/ ICM records
  - **Review and submit to NS Forms**

Review and Submit to NS Forms: Documents will need to be digitized/ scanned after each data collection

Study Timeline: Roles and Responsibilities

DSP QoL Research Study

Any questions you would like to discuss together?

Participant living in a care facility

We are **here**

Data collection happening on average every ~6 months

Transition

Participant moves out and starts settling into community living

First post-transition data collection to happen within **~1 or 2 months after moving out**

Data collection **continues** with an **average of every ~6 months**

If, at any data collection moment, the Participant wishes to drop out:

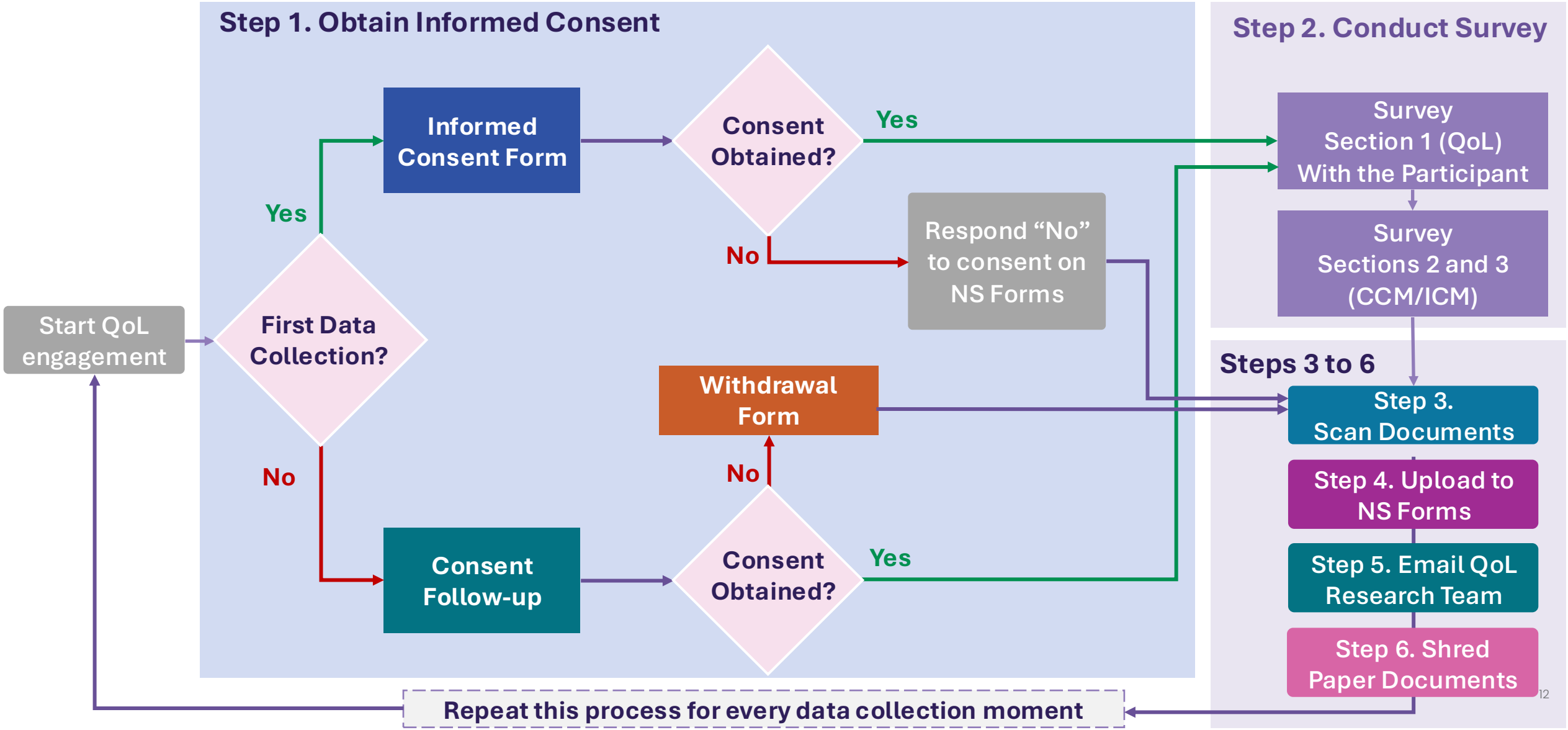
- Ensure the study participant knows what withdrawing means
- Conduct withdrawal process using the **Withdrawal Form**
- **Review and submit to NS Forms**

Review and Submit to NS Forms: Documents will need to be digitized/ scanned after each data collection

Overview of Each Data Collection

DSP QoL Research Study

Any questions you would like to discuss together?



First Data Collection Moment

Step 1. Obtain Informed Consent
with **Informed Consent Form**

Materials to Support Data Collection

First Data Collection Moment

Any questions you would like to discuss together?

Here are the materials that will support you at each data collection moment.

What Do I Bring to the First Data Collection Interaction?

For your first data collection interaction, you will only need the **Informed Consent Form** and the **Survey**:

	Informed Consent Form	Consent Follow-Up	Survey	Withdrawal Form
Elements	**Includes:** ▪ Instructions (for IPSCs) ▪ Form (for Participants) ▪ Signature Page (for both)	**Includes:** ▪ Form (for Participants) ▪ Signature Section (both)	**Includes:** ▪ Instructions (for IPSCs) ▪ Section 1 (for Participants) ▪ Section 2 (for IPSCs) ▪ Section 3 (for IPSCs) **Unique Survey ID #**	**Includes:** ▪ Signature Page (for both)

What Do I Need to Keep After the Data Interaction?

You will <u>need</u> to keep hold of the:

- **Informed Consent Form Signature Page** (IPSC Version)
- **Survey Sections 1 – 3**

! Paper versions of these materials to be shredded **after uploaded to NS Forms** platform.

Purpose and IPSC Responsibility

Step 1. Obtain Informed Consent

Step: 1 – 2 – 3 – 4 – 5 – 6

Purpose: Ensuring study participants understand the Research Study and to consent to participate, if they wish to.

Why is obtaining informed consent necessary?

Obtaining **informed consent** is a process that ensures participants know and understand:

- What the study is about and what will happen if they participate,
- Any possible benefits and risks of participating,
- That their participation is voluntary and completely their choice,
- That they can stop participating at any time, without any consequences.

Only DSP participants who agree to participate should be engaged as their participation is voluntary.

Your responsibility

It is important to know that the **DSP participant can always refuse to participate in the research study at any time**.

If the participant initially provides consent and then changes their mind, this must be respected, and you must withdraw them from the research study immediately.

The research study will not implicate you or the DSP participants that you are supporting in any way.

All personal information will be collected securely.

Ensuring DSP Participant Awareness

Step 1. Obtain Informed Consent

Step:

1 2 3 4 5 6

Obtaining Genuine Consent

Sometimes, people say ***"yes"* even if they do not really agree or understand**. This can happen if they want to please you or think there is a right answer. **This is a known response bias** that can indicate a person may not be ready or able to answer.

Validate their Understanding

If there is any **doubt whether the DSP participant that you are supporting has understood what they have been told**, we encourage you to ask a question where you know the correct answer is **"no"**.

If their response is yes (instead of the accurate "no"), then the person may not have understood the consent process.
Example questions you can ask to check for response bias:

- Do you make all the clothes that you wear?
- Did you paint all the walls in this room?
- Do you deliver all the mail in your community?

?

What do I do?

- If you feel comfortable that the person **is not experiencing this response bias:** Proceed to the asking them for their consent.
- **If you believe they are displaying a response bias:** Complete the Signature Form for them as "No – I do not agree".

Informed Consent Overview

Step 1. Obtain Informed Consent

Step: 1 – 2 – 3 – 4 – 5 – 6

Objective: Obtain informed consent if the DSP participant is **willing and able** to become a study participant.

Required Materials: **Informed Consent Form**

Informed Consent Form:
- To guide the Informed Consent
- For Participants to keep

- Use the form to introduce the QoL research study
- Read out loud the Q&A format
- **Does the DSP participant appear to understand?** You may need to see if they can provide consent.
- Does the DSP participant show willingness to join the research study?
- Once you have read the form, you can progress to the **Signature Page**

Informed Consent Form – for DSP Participants

1. What is happening?

You are being asked to be part of a research study that looks at quality of life – which means how good life feels to you – as you will soon be moving from your current home and into a new place in community.

1.1. Who is doing this research study? The research study is being done by the Disability Support Program (that you are included in) and by a research team (including people who work at the Disability Support Program and at Davis Pier Consulting) that will help run the study.

1.2. What is this research study about? The research study is about understanding how you feel. We want to know if you feel happy or sad, relaxed or worried. You will be moving from your current home into a new place in community. We want to know how you feel throughout this change.

Here you can find more information about the research team and the study:

- The research team includes Maria Medioli (Project Sponsor); Michelle Harris; Dawn Whitty; Raquel Rosas, PhD; Eliza-Jane Stringer; MSc, James Goddard, MSc; Martin Day, PhD. The Principal Investigator from the research team is Raquel Rosas (Davis Pier).
- If you have questions about the research study, you can contact (or ask your DSP Support Person to help you contact) the research team at any time by using the email DSP-QOL@novascotia.ca
- If you have questions or concerns about your rights as a participant in the study, you can contact (or ask your DSP Support Person to help you contact) the Health Research Ethics Board. This is a group that reviews research studies to make sure they are safe and respectful. You can reach them at the email info@hrea.ca

Possibility 1: Consent is Given

Step 1. Obtain Informed Consent

Step: 1 – 2 – 3 – 4 – 5 – 6

It is standard practice in research studies that **you must obtain a formal indication of informed consent** which shows that the individual wants to participate in the study. This is is achieved with a **Signature Page**.

There will be 2 copies of the **Signature Page**:

- **An IPSC version:** This will be kept for you to digitize and submit to the research team,
- **A participant version:** This will be kept with the DSP participant.

Signature Page:
1x Participant to keep
1x IPSCs to digitize

Informed Consent Signature Page

Survey ID: _____

Do you agree:

(a) to **participate** in the study?
(b) to allow the Disability Support Program (that you are included in) to share your **personal information** and the **support level you receive** to the research team (Davis Pier) for the study?
(c) to allow DSP and the research team (Davis Pier) to **collect** and **use** your **personal information for the study**?

Consent Options

☑ Yes – I agree ☐ No – I do not agree

If you check 'Yes – I agree', it means:

(a) You understand what this study is about
(b) You want to be in the study
(c) You agree to share your information

Name of Participant: _____

Signature: _____ **Date:** ___ (DD) ___ (MM) ____ (YYYY)

CCM Identifier: _____

Name of Person Obtaining Consent (IPSC): _____

Signature (IPSC):_____ **Date:** ___ (DD) ___ (MM) ____ (YYYY)

Clear Sign of Consent

If the DSP participant is able to consent and wants to participate, you will **ask the DSP participant for a signature**. If they cannot sign then a mark, stamp, or verbal communication with the signature of a witness is acceptable.

Signing, or using another acceptable format, shows that the DSP participant agrees to the informed consent and agrees to participate in the study.

Do we (IPSC and DSP participant) Need to Sign Both copies?

Yes. Both the IPSC and DSP participant must sign both copies.

The DSP participant will keep one as a receipt and you will upload (into NS Forms) the one you keep.

Possibility 2: Consent is not Given

Step 1. Obtain Informed Consent

Step: 1 – 2 – 3 – 4 – 5 – 6

What if a DSP participant does not want to participate?

If this happens, the DSP participant will **not become a study participant,** but you still need to complete the Signature Page with the DSP participant so that DSP can track who is a study participant and who is not.

The difference is that you will tick "No – I do not agree" on the **Signature Forms** – you will still submit this to the NS Forms platform.

Signature Page:
1x Participant to keep
1x IPSCs to digitize

Informed Consent Signature Page

Survey ID: _____

Do you agree:

(a) to **participate** in the study?
(b) to allow the Disability Support Program (that you are included in) to share your **personal information** and the **support level you receive** to the research team (Davis Pier) for the study?
(c) to allow DSP and the research team (Davis Pier) to **collect** and **use** your **personal information for the study**?

Consent Options

☐ Yes – I agree ☒ No – I do not agree

If you check 'Yes – I agree', it means:

(a) You understand what this study is about
(b) You want to be in the study
(c) You agree to share your information

Name of Participant: _____

Signature: _____ **Date:** ___ (DD) ___ (MM) ____ (YYYY)

CCM Identifier: _____

Name of Person Obtaining Consent (IPSC): _____

Signature (IPSC):_____ **Date:** ___ (DD) ___ (MM) ____ (YYYY)

End of DSP participants engagement

Under these circumstances, this DSP participant will no longer participate in the study.

This process will operate very similarly for **all subsequent data collection interaction;** they will stop participating and all previously held information in the study regarding them will promptly be deleted.

What Does This Mean for the DSP Participant?

Nothing will change for the DSP participants care and support system.

They will continue through the transition process in an otherwise identical manner.

Inform Consent Summary

Step 1. Obtain Informed Consent

Step: 1 – 2 – 3 – 4 – 5 – 6

The process of obtaining informed consent is the most important step in each data collection interaction as you want to ensure that the study participant is genuinely willing and able to participate in the research study. This ensures the research study is ethical.

Important: This tool is made of **two equal pages** – one to stay with the DSP participant, one to be digitized and submitted to the research team.

Informed Consent Checklist

- ✓ Read out loud Q&A format to the study participant
- ✓ Check to see if the study participant can continue **providing genuine consent**
- ✓ Engage with, and answer any questions, raised by study participant
- ✓ Obtain a signature/ mark from study participant (on both pages)
- ✓ Fill in all other fields in Signature Pages (on both pages)
- ✓ Add the **Survey ID** of the paper survey that the participant will be answering

Signature Page

Informed Consent Signature Page

Survey ID: _____

Do you agree:

(a) to **participate** in the study?

(b) to allow the Disability Support Program (that you are included in) to share your **personal information** and the **support level you receive** to the research team (Davis Pier) for the study?

(c) to allow DSP and the research team (Davis Pier) to **collect** and **use** your **personal information for the study**?

Consent Options

☐ Yes – I agree ☐ No – I do not agree

If you check 'Yes – I agree', it means:

(a) You understand what this study is about

(b) You want to be in the study

(c) You agree to share your information

Name of Participant: _____

Signature: _____ **Date:** ___ (DD) ___ (MM) ____ (YYYY)

CCM Identifier: _____

Name of Person Obtaining Consent (IPSC): _____

Signature (IPSC):_____ **Date:** ___ (DD) ___ (MM) ____ (YYYY)

All Data Collection Moments

Step 2. Conduct Survey

Quality of Life Survey

Step 2. Conduct Survey

Step:

1 – 2 – 3 – 4 – 5 – 6

Once a **Signature** (or alternative and satisfactory form of confirmation) has been obtained, you can then start the survey interaction with the study participant.

Data Collection Instructions

To help you through the process there are **supporting instructions** specific to the data collection step, these reflect all the information that you see in these slides, so you will have a copy of all the steps involved in the data collection process.

Survey Pre-Checklist

Before you conduct the survey, you must:

- ✓ Read and Review the **Survey Instructions** to before you starts
- ✓ Ensure you have collected **genuine informed consent**
- ✓ Collect a **clear signature/ mark** from the study participant
- ✓ Ensure you have a **printed, colored copy of the Survey** that will be provided to you when meeting the DSP participant
- ✓ Preferably you should have a **pencil and an eraser** in case the study participant changes their mind

Instructions:
To support IPSCs
For IPSCs to keep

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 Informed Consent

- Review the Informed Consent Form with the DSP Participant (and guardian/proxy, if needed). 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 (participant and/or proxy, and IPSC/witness).
- You will need **2 signed copies** of the **Informed Consent Signature Page** – one to be submitted to the Research Team and another to stay with the Study Participant.

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

- Bring a printed copy of the survey (pages 3 to 9) when meeting the Participant.

Section 1: Quality of Life (1 of 2)

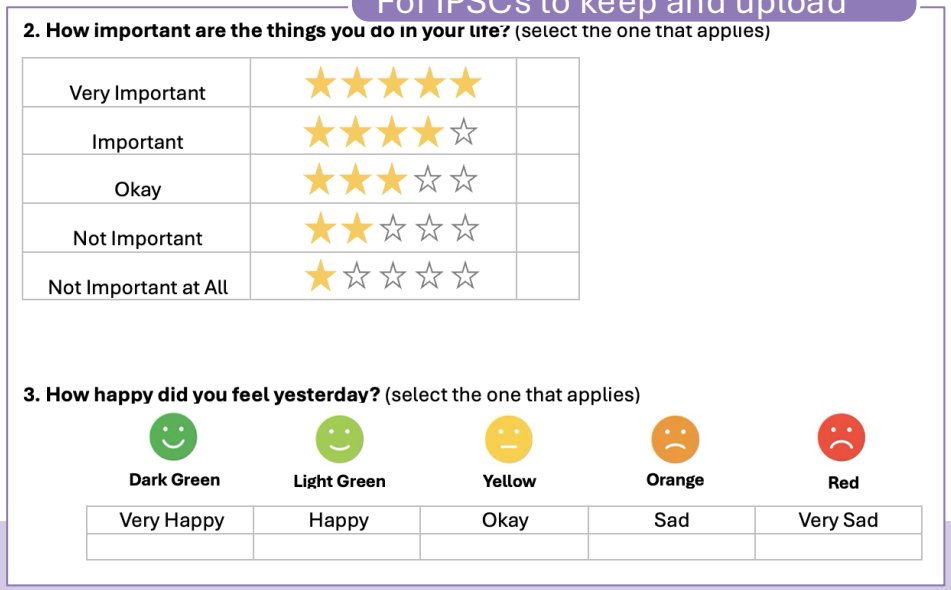
Step 2. Conduct Survey

Step:

1 – 2 – 3 – 4 – 5 – 6

Section 1 of the **Quality of Life Research Study** includes pages 3 to 8 in the **Survey**.
There are only 13 questions to answer in this section.

Section 1:
To collect data from Participants
For IPSCs to keep and upload



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

How do I Conduct this Survey?

- **Guide the study participant through each question.** Feel free to show them all the questions before answering any
- **If they can complete the survey by themselves** (i.e., using a pencil) then encourage this! If not, you will write down the answers for them
- **Show them the visuals as much as possible**
- **Questions 11 and 13 allow for long-form answers** - this means that they can write/draw any other things they want to share

Data Collection Tips

- **Read out load clearly and slowly.**
- There will be additional wordings and examples to help explain a question or concept.
- **There are no mandatory questions.**
- Allow time for answers, do not rush. **Record answers exactly as given.**

Sections 2 and 3: Quality of Life (2 of 2)

Step 2. Conduct Survey

Step:

1 – 2 – 3 – 4 – 5 – 6

Sections 2 and 3

Participant CCM Identifier: _____ Date: ___ (DD) __

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

_____

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

Sections 2 and 3 have a place to take note on the presence of other individuals in the room during data collection

- Keep track of the **roles** (NOT names) of the individuals who are present in the room during the survey interaction
- E.g., if another IPSC was present, you would add "IPSC"
- ***Why monitoring this?*** The presence of others may impact survey responses from the participant. To ensure we keep data collection as transparent as possible, this information is important to collect.

You do not need to remember all of this – both the **survey instructions and materials have all this information** on it.

Section 2: About the Participant

Step 2. Conduct Survey

Step:

1 – 2 – 3 – 4 – 5 – 6 →

Data Collection using Case Management Records

The remaining two sections of the survey refer to information on the DSP participant and their transition stage.

These are **only for you as the IPSC to fill out**.

At this point, the involvement of the DSP participant is finished for this data collection round.

- The responses to these questions will be found in and aligned to the **ICM/ CCM records**.
- If you struggle to find any information, **contact your IPSC Team Lead**

Section 2

Survey | Section 2: *About the Participant* – for ISPC to complete

These questions will help us understand more about the participants while maintaining complete anonymity. 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. How much do you agree with the statement:

"The participant appears to have a supportive family/ friend network"? (select with an **X** the one that applies)

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Don't know/ Unsure

Section 3: About the Transition Process

Step 2. Conduct Survey

Step:

1 – 2 – 3 – 4 – 5 – 6

- This section collects information on the transition process of the study participant.
- At the end of this section, there is a **Feedback Box**.

  You can use the **Feedback Box** to mention any outstanding or important things to note about the data collection interaction (e.g., clarifying answers, feedback on survey process).

Section 3

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

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

Yes		(select if applies)
No		(select if applies)
I don't know		(select if applies)

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

Date:		
I don't know		(select if applies)
Not Applicable		(select if applies)

25. 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.).

Before Completing...

Make sure you review and are satisfied with all the information that you have collected.

If you need help, remember that you can ask your IPSC Team Lead for support!

All Subsequent Data Collection Moments

Step 1. Obtain Informed Consent
with **Consent Follow-Up**

Materials to Bring

All Subsequent Data Collection Moments

Any questions you would like to discuss together?

What do I bring to all Subsequent Data Collection Moment?

For all subsequent data collection interactions, you will need the **Consent Follow-up**, **Survey**, and **Withdrawal Form** materials.

	Informed Consent Form	Consent Follow-Up	Survey	Withdrawal Form
Elements	**Includes:** ▪ Instructions (for IPSCs) ▪ Form (for Participants) ▪ Signature Page (for both)	**Includes:** ▪ Form (for Participants) ▪ Signature Section (both)	**Includes:** ▪ Instructions (for IPSCs) ▪ Section 1 (for Participants) ▪ Section 2 (for IPSCs) ▪ Section 3 (for IPSCs) **Unique Survey ID #**	**Includes:** ▪ Signature Page (both)

What do I Need to Keep After the Data Interaction?

You will <u>need</u> to keep hold of the:

- **Consent Follow-up Signature Section** OR **Withdrawal Form** (IPSC Version)
- **Survey Sections 1 – 3**

! Paper versions of these materials to be shredded **after uploaded to NS Forms** platform.

Informed Consent Follow-Up (1 of 2)

Step 1. Conduct informed Consent Follow-Up

Step: 1 – 2 – 3 – 4 – 5 – 6

Objective: Ensuring study participants keep providing their consent to participate, if they wish to.

Required Materials: **Informed Consent Follow-up**, **Withdrawal Form**

Important: This tool is also made of **two equal pages** – one to stay with the DSP participant, one to be digitized and submitted to the research team.

Informed Consent Follow-up Checklist

- ✓ Read out loud the Q&A format to the study participant
- ✓ Check to see if the study participant can continue **providing genuine consent**
- ✓ Engage with, and answer any questions, raised by study participant
- ✓ Obtain a signature/ mark from study participant if consenting (on both pages of **Signature Section**)
- ✓ Fill in all other fields in **Signature Section** (on both pages)
- ✓ Add the **Survey ID** of the paper survey that the participant will be answering

Form and Signature Page:
1x Participant to keep
1x IPSCs to digitize

Survey ID: _____

Informed Consent Follow-Up

1. Refresher for the Quality of Life Research Study: This is a follow-up to a research study where you are being asked to continue to be a part of a research study that looks at quality of life – which means how good life feels to you.

2. Do you still want to be a part of this research study? You can choose to say no. No one will be upset if you choose to no longer take part. If you say no, the research team will stop holding your answers and remove any previous answers you may have provided us with. This information will be removed as quickly as possible.

3. What questions will you be asked? You will be asked the same questions as before. Nothing will come as a surprise to you.

3.1. Why are you being asked the same questions? Asking you the same questions allows us to understand whether your thoughts and feelings have changed from the last time you answered the questions.

3.2 What if you answer differently from last time? Our feelings can change. There are no wrong answers! You can tell us how you feel right now.

4. What are your choices?

You can:

- **Think** about it and take more time before answering.
- **Talk** about it to some you trust. Like your friends, family, and DSP Support Person.
- **Ask** questions. Your DSP Support Person and the research team are here to help you.
- **Decide to participate,** if you want to be in the study.
- **Decide to stop participating**, if you do not want to be in the study anymore.

If you are ready to decide about your participation, you can choose to:

Withdraw from the research study ⟷ **Continue to take part in the research study**

Informed Consent Follow-up: Signature Section

Do you agree to continue participating in this research study?

Name of Participant: _____

Signature: _____ **Date:** ___ (DD) ___ (MM) ____ (YYYY)

CCM Identifier: _____

Name of Person Obtaining Consent (IPSC): _____

Signature (IPSC):_____ **Date:** ___ (DD) ___ (MM) ____ (YYYY)

Informed Consent Follow-Up (2 of 2)

Step 1. Conduct informed Consent Follow-Up

Step:

1 2 3 4 5 6

The process for obtaining **informed consent** in all subsequent data collection interactions are very similar to the first interaction, but not identical.

How are the Informed Consent Form and Informed Consent Follow-up Similar?

1. Both materials are to obtain informed consent from the study participant
2. Both provide a **Question-and-Answer format** to help explain the study to the study participant
3. Both have Signature Pages/ Sections for the IPSCs and study participants to sign/ mark

How do they Differ?

There are two main ways in which the **Informed Consent Follow-up** differs:

1. IPSCs will use the **Informed Consent Follow-up** material to re-obtain consent from the study participant
   - This document is a brief version of the **Informed Consent Form**
   - It also acts as a refresher
2. The **Withdrawal Form** will also be available, in case the study participant chooses to withdraw

Study Participant Wants to Stop Participating

Steps for Withdrawal Form

Withdrawal Form (1 of 2)

What if the Participant no Longer Wants to Participate?

Any questions you would like to discuss together?

Purpose: In case a study participant does not want to continue participating, a **Withdrawal Form** must be completed to help ensure that they (the participant) is no longer a part of the study.

Why do we Need to Complete This Withdrawal Forms?

The withdrawal form ensures that DSP can record who is in the research study and who is not. If a person changes their mind, DSP needs to ensure this is recorded to respect their decision going forward.

What is Required for the Withdrawal Form?

- ✓ Confirm with the study participant what withdrawing means
  - No longer going to be asked questions
  - Removal of all their answers and any personal information shared with the research team – both past and present
- ✓ **The IPSC will sign the withdrawal form** to indicate that the DSP participant has withdrawn – a DSP participant signature is optional
- ✓ Fill in all other fields in **Withdrawal Form** (on both pages)

!

A study participant can request to withdraw <u>any time</u> during the study.

Form and Signature Page:
1x Participant to keep
1x IPSC to digitize

Withdrawal Form – DSP Participant Version

A withdrawal form is a short document your DSP Support Person will use to record your decision of **no longer wanting to take part in the study**. Its purpose is only to let the research team know that you wish to stop taking part in the study and no longer want to be invited to respond to the survey.

You can keep a copy of this Withdrawal Form for yourself, as a record of your decision to stop participating in this study.

Your DSP Support Person will sign this Form to register your decision. You can also sign this Form, if you wish to. Your signature is completely optional and your request to stop participating will be register whether or not you decide to sign this Form.

By completing this form, your DSP Support Person (your IPSC) is making a record that you want to **withdraw** from the DSP Quality of Life research study. This means that:

(a) You will no longer be a part of this study,
(b) You will no longer be invited to respond to the survey, and
(c) Your personal information and support level information will no longer be provided to the research team (Davis Pier).

Withdrawal Confirmation

☐ Yes – I (the participant) want to withdraw from the study and no longer respond to the survey

Name of Participant: _____
(in BLOCK CAPITALS)

Participant Signature (optional): _____
Date: ___ (DD) ___ (MM) ____ (YYYY)

Collaborative Case Management (CCM) Identifier: _____

Name of Person Obtaining Consent (IPSC): _____
(in BLOCK CAPITALS)

IPSC Signature (mandatory):_____

Date: ___ (DD) ___ (MM) ____ (YYYY)

Withdrawal Form (2 of 2)

What if the Participant no Longer Wants to Participate?

Any questions you would like to discuss together?

What Happens After the Withdrawal Form has been Signed?
Once the **Withdrawal Form** has been signed you must inform the research team.

This will be achieved by **using the NS Forms survey to transfer the information from the paper survey**.

1. The first question on the NS Forms will ask **if the DSP participant provided consent** to participate or continue participating in this research study.
   - **You will choose the option "No"**
2. The NS Forms platform will then request you to provide proof of the **Withdrawal Form**.
   - **You will upload the scanned IPSC version of the Withdrawal Form clearly marked with the scanner Icon**
3. The online upload of the Withdrawal Form is then complete.

After Collecting Data

Overview of Steps 3 to 6

Concluding the Data Collection Process

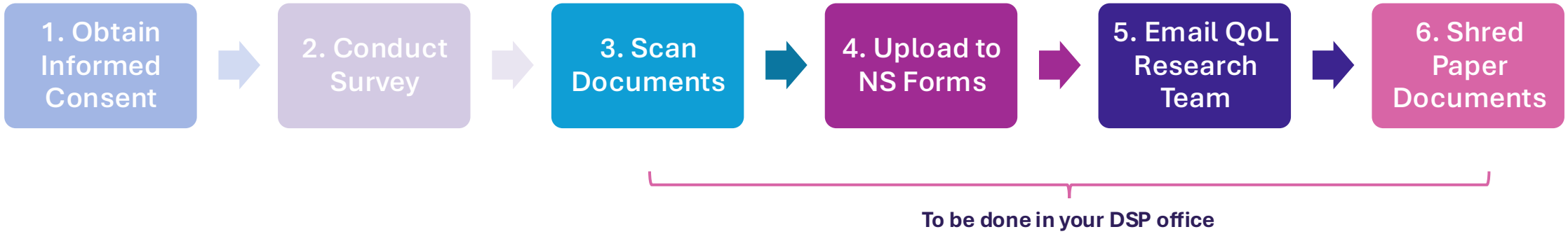
DSP QoL Research Study

Overview of Steps:

To summarize all post-survey interactions that are included in Steps 3, 4, 5, and 6:

Post-Survey Checklist

- ✓ Scan the **Signature Page/ Section/ Withdrawal Form**
- ✓ Scan the long-form text box question pages (if filled in)
- ✓ Upload the scanned documents and fill in all survey information to the **NS Forms platform**
- ✓ **Send confirmation email to research team** – wait for acknowledgement of receipt before next step
- ✓ **Shred any paper documents with personal information** – if in doubt, shred
- ✓ Delete all digitized documents from Recycle Bin/ Trash



Scanning: From Paper to Digital Copies (1 of 2)

Step 3. Scan Documents

Step: 1 2 3 4 5 6

A part of the data collection process will involve digitizing some of the pages by scanning them.

These pages are clearly marked with the following **Scanner Icon**:

How Can I Scan These Pages?

To scan any pages indicated with the above Scanner Icon **you must go to your DSP Office** where you can find the scanners that can link to your DSP-provided laptop. This will ensure that any personal information on these files are only ever on DSP devices.

Important Notes

1. Do not use any other personal scanner or digitization methods to create digital copies of the required pages.

It is okay if you need to wait to return to your nearest DSP office

2. Once you have uploaded all necessary digital copies to the NS Forms survey platform you must **delete these files from your DSP laptop**

Scanning: From Paper to Digital Copies (2 of 2)

Step 3. Scan Documents

Step: 1 – 2 – 3 – 4 – 5 – 6

The **Scanner Icon** is located on the materials in the exact sections/pages that need to be scanned

What Documents Must be Scanned?

You must upload:

- **Consent documentation:** A scanned version of any consent-related documents you are using at the time.

  This might be:

  ✓ the **Signature Page** from the Consent Form (1st moment), or

  ✓ the **Signature Section** from the Follow-Up Form (subsequent times), or

  ✓ the **Withdrawal Form** (if dropping-out)
- **Survey documentation:** Scanned versions of the **long-form text box questions**

Informed Consent

Informed Consent Signature Page – IPSC Version

Do you agree:

(a) to **participate** in the study?

(b) to allow the Disability Support Program (that you are included in) to share your **personal information** and the **support level you receive** to the research team (Davis Pier) for the study?

(c) to allow DSP and the research team (Davis Pier) to **collect** and **use** your **personal information for the study**?

Consent Options

☐ Yes – I agree ☐ No – I do not agree

If you check 'Yes – I agree', it means:

(a) You understand what this study is about

(b) You want to be in the study

(c) You agree to share your information

Name of Participant: _____
(in BLOCK CAPITALS)

Signature: _____ **Date:** __ (DD) __ (MM) ____ (YYYY)

CCM Identifier: _____

Name of Person Obtaining Consent (IPSC): _____
(in BLOCK CAPITALS)

Signature (IPSC): _____ **Date:** __ (DD) __ (MM) ____ (YYYY)

Survey ID: ☐☐☐

Consent Follow-Up Signature Section

Informed Consent Follow-up: Signature Section

Do you agree to continue participating in this research study?

Name of Participant: _____
(in BLOCK CAPITALS)

Signature: _____ **Date:** __ (DD) __ (MM) ____ (YYYY)

CCM Identifier: _____

Name of Person Obtaining Consent (IPSC): _____
(in BLOCK CAPITALS)

Signature (IPSC): _____ **Date:** __ (DD) __ (MM) ____ (YYYY)

Survey ID: ☐☐☐

Withdrawal Form

Withdrawal Form – IPSC Version

A withdrawal form is a short document you can complete **if you decide you no longer want to take part in the study**. It lets the research team know that you wish to stop and tells us what you would like us to do with any information you have already shared.

By signing or marking this form you are asking to **withdraw** from the DSP Quality of Life research study. This means that:

(a) You will no longer be a part of this study,

(b) Your personal information and support level information will no longer be provided to the research team (Davis Pier)

(c) Any previous information provided will be deleted upon receipt of signed withdrawal form.

Withdrawal Confirmation

☐ Yes – I would like to withdraw

Name of Participant: _____
(in BLOCK CAPITALS)

Signature: _____ **Date:** __ (DD) __ (MM) ____ (YYYY)

CCM Identifier: _____

Name of Person Obtaining Consent (IPSC): _____
(in BLOCK CAPITALS)

Signature (IPSC): _____ **Date:** __ (DD) __ (MM) ____ (YYYY)

Survey ID: ☐☐☐ **(Optional)**

Survey Text Box Questions

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 box below:

Nova Scotia Forms

Step 4. Upload to NS Forms

Step:

1 2 3 4 5 6

To help collect all the data one of the tools that you as IPSCs will need to use is a survey platform called Nova Scotia Forms – or NS Forms.

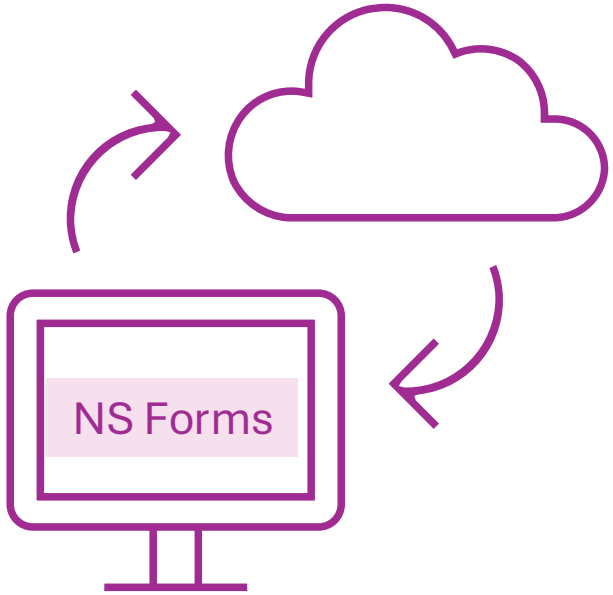
Why do I need Paper Copies if this Information is to be Uploaded?

In-Person Benefits

You will be **interacting with the study participant with paper versions** of the materials because the **physical face-to-face interaction** can help conduct the survey.

Digital Security

However, **all data must be stored safely and securely** in a centralized location. This is why you are requested to upload all response (i.e., the informed consent and survey materials) to NS Forms.



?

What is NS Forms?

- **NS Forms is a Nova Scotia-approved governmental survey platform.**
- **It ensures that the collection and handling of personal information remains safe and secure.**

Upload the Documents

Step 4. Upload to NS Forms

Step:

1 2 3 **4** 5 6

What do I Submit onto NS Forms?

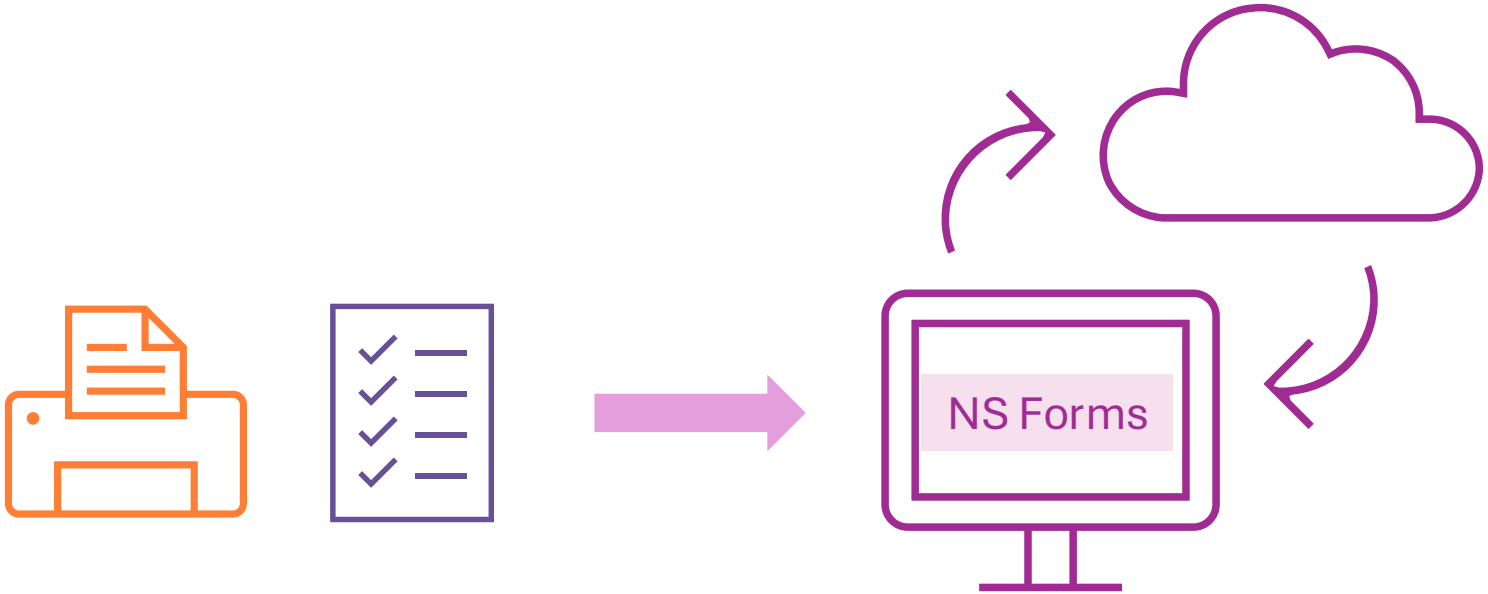
You will then submit the following documents and information to the NS Form:

- Your **scanned** version of the Signature Page/ Section/ Withdrawal Form
- Your **scanned** version(s) of the long-form text box questions (if applicable)
- All the survey responses across all survey sections:
  - **Section 1: Quality of Life**
  - **Section 2: About the Participant**
  - **Section 3: About the Transition Process**

!

What if my participant is not consenting to participant OR withdrawing from the study?

- These instructions apply to **every scenario** you may find yourself in.



Confirm Submission (1 of 2)

Step 5. Send Email to QoL Research Team

Step: 1 2 3 4 **5** 6

After uploading the survey information to the NS Forms platform, you will need to **send an email to the research team** to **confirm submission to NS Forms**. This email is to confirm you submitted information through the NS Forms platform.

What if the Participant declines to participate or wants to withdraw from the study?

An email should be sent to the Research Team regardless of the data collection scenario.

1. **Consent is provided:** Email to confirm consenting information (from the Consent Form or Follow-Up) and survey information were uploaded to NS Forms
2. **Consent is not provided:** Email to confirm Consent Form or Follow-up (showing declining to participate) were uploaded to NS Forms
3. **If a withdrawal is requested:** Email to confirm Withdrawal Form was uploaded to NS Forms

After submitting information through NS Forms, you should **email the Research Team** (DSP-QOL@novascotia.ca).

The **QoL Research Team** will **reply to confirm the reception** and reach out if anything requires a new upload.

Confirm Submission (2 of 2)

Step 5. Send Email to QoL Research Team

Step:

1 – 2 – 3 – 4 – **5** – 6

What do I need to write in the email?

Confirmation emails are short and simple. According to the scenario you have, you can simply send the following:

1. Consent Provided:

Email Subject: “Survey ID ####”

Email text: “Submitted consent and survey IDs ####, #####, etc.”.

2. Consent is Not Provided:

Email Subject: “Consent Rejection”

Email text: “Submitted X consent rejection(s)”.

3. If Withdrawal is Requested:

Email Subject: “Withdrawal”

Email text: “Submitted X withdrawal(s)”.

Can I send one email to confirm multiple submissions to NS Forms?

Yes, you can send just 1 email to refer more that one submission to NS Forms – e.g., “Survey ID ####, XXXX, and ZZZZ”

If you have different scenarios (e.g., 1x Consent not provided and 2x Withdraw requests), you can also send just one email– just make sure you **mention all those different scenarios in the email text**.

!

Important

Do not use any personal information – such as the participants CCM ID – in these email communications.

Shredding All Paper Copies

Step 6. Shred & Delete All Copies

Step:

1 2 3 4 5 6

Destroy the Paper Documents Containing Personal Information

The paper survey and all consent documentation (including signature pages) hold sensitive information and need to be disposed of appropriately.

This means the following paper copies will be shredded at your respective DSP office:

- **The full Survey**
- **Consent documentation:** The IPSC copy of the **Signature Page** (Informed Consent), the **Signature Section** (Consent Follow-Up), or the **Withdrawal Form**

How Soon Should I Destroy These Documents?

You should shred the documents as **promptly as possible** once submitting all the information on NS Forms since these surveys have **sensitive information regarding the DSP participant.**

What if I Cannot Destroy These Documents Immediately?

It may be that you need to hold on to the documents.

If this is the case, you will be requested to hold onto the paper documents **in a secure manner**, such as in a folder physically nearby you, and **in a secure location**, such as your DSP office.

How Long is Too Long to Wait Before Destroying These Documents?

If you are unable to access a shredder **within a week** of a data collection interaction, please inform your DSP Team Lead.

Deleting All Digital Copies

Step 6. Shred & Delete All Copies

Step: 1 2 3 4 5 6

After you have uploaded the information into the NS Forms survey you may still have the digital copies on your DSP laptop.

Is it essential that you **delete these digital copies completely** once they have been submitted and receipt has been confirmed by the research team.

This means you must:

- **Move the documents to Recycle Bin on the computer you are using**
- **Go to your Recycle Bin**
- **Then delete the file from here**

Files that were scanned and need to be deleted:

- **Consent documentation –** The paper version of:
  - ✓ the **Signature Page** from the Consent Form (1st moment), or
  - ✓ the **Signature Section** from the Follow-Up Form (subsequent times), or
  - ✓ the **Withdrawal Form** (if dropping-out)
- **Survey documentation:** Scanned versions of the **long-form text box questions**

IPSCs and Research Team Communication

Confirmation Email & Monthly Reminder Email

Ongoing Communication Support

IPSCs and Research Team Communication

Any questions you would like to discuss together?

In addition to **Step 5. Send Email to QoL Research Team**, there will be other communications between IPSCs and the Research Team.

The Research Team will send out **monthly email communications to all IPSCs and IPSC Team Leads**.

The emails will include:

- **Upcoming data collections for each IPSC**
- **Notes from the Research Team for support and ongoing clarifications**

The emails will **not** include:

- **CCM identifiers**
- **DSP participant names**

What is the Purpose of these Communications?

This will be done to ensure that no DSP participants that have consented to the research study are missed in the data collection process.

What if I or Study Participants Have Questions or Additional Need for Support?

For additional clarifications and questions, you can connect with your Team Lead and/or reach out to the Research Team (DSP-QOL@novascotia.ca)

Integration with IPSC Tracker

IPSCs and Research Team Communication

Any questions you would like to discuss together?

To help keep a record of this on the front-line operations side, IPSC Team Leads will also be including key transition data in the **IPSC Tracker**.

Offered HomeShare? (Y/N/NA)	Last Update (YYYY-MM-DD)	1 DSP-QOL Active Study Participant	2 DSP-QOL Last Data Collection (YYYY-MM-DD)	3 DSP-QOL Upcoming Data Collection within 6M Cadence (YYYY-MM-DD)	4 DSP-QOL Data Collection 1-Month after Move Out	5 Expected or Done Date, If Known (YYYY-MM-DD)	Notes
		Yes	2026-01-01	2026-07-01	Expected (Include Date)	2026-09-01	
		No					

Entries used as an example – not real entries

1. Currently participating in the DSP QoL Research Study
2. Last time data was collected
3. Next time data will be collected
4. Tracking data collection post-moving out as:
   - Not known yet
   - Expected
   - Done
5. Tracking data collection post-moving out as:
   - If expected, when (YYYY-MM-DD)
   - If done, when (YYYY-MM-DD)

Roles and Responsibilities

How IPSCs Can Support this Study

1. Informed Consent → 2. Conduct Survey → 3. Scan Documents → 4. Upload to NS Forms

	Before Starting	During Data Collection	Scan	Upload	Subsequent Times
Actions	**1. Conduct the Informed Consent process** ✓ Check for ability to consent ✓ Check for Response Bias ✓ Contact Research Team using DSP-QOL@novascotia.ca, if additional support is needed	**2. Conduct the Survey** ✓ Section 1: QoL (Participants) ✓ Section 2: About the Participant (IPSCs) ✓ Section 3: About the Transition Process (IPSCs)	**3. Scan Documents** Consent pages and Survey text boxes **4. Submit to NS Forms** ✓ Consent Signature Pages ✓ Survey (filled out): Transcribing survey information		**1. Informed Consent Follow-up** **2. Conduct the Survey** **3. Submit Materials** **Team Leads** will give you Monthly Reminders for upcoming data collection
Processes	**If consent is given:** Signature Page to be signed/marked by consenting participant **If consent is not given:** Participant to not be included	**Section 1:** IPSC to guide participant and record the answers **Sections 2 and 3:** IPSC to respond to questions with available information	▪ **Survey and Consent documents:** Indicate the Participant CCM Identifier ▪ **On Survey:** Role/job title of others in the room		▪ Team Leads: Monthly reminders for upcoming data collection activities ▪ Consent Follow-up for all subsequent collections
Materials	▪ Informed Consent Form incl. Signature Page (IPSC + Participant) ▪ Survey (IPSC + Participant)	▪ Survey (IPSC + Participant)	▪ Signature Page of Informed Consent Form (signed/marked by consenting participant) ▪ Survey (IPSC + Participant)		▪ Informed Consent Follow-up ▪ Withdrawal Form ▪ Survey

5. Email QoL Research Team → 6. Shred Paper Documents

Open Discussion

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Thank You