iUnite Guide – Understanding the Evaluation & Research Process

Two separate evaluation and research projects are underway:
- **Howegroup** (evaluation) – analyzing anonymized data collected from PART I, II, & III to produce a report on this demonstration project/period (Jan 2020-Jun 2022)
- **UBC** (research) – reviewing anonymized data collected from PART I, II, & III and participants' individual PHN to look into changes in the use of medical and health services over time (before, during and after demonstration project)

Personal Information Collection & Consent to Participate in Research
- Why do we need their PHN?
  - The Personal Health Number will be entered into a form stored within the secure search portal at Population Data BC (PopData).
  - Researchers will look at how participants use FFCSP/TAPS/SPP, home and community care, doctor visits, hospital stays, prescriptions, and trips to the emergency department.
  - Participant name and other identifying information will be removed from the data before the research team has access to it.
- At intake (or whenever coordinator feels comfortable), participants will be asked for 3 consents (verbal consent is acceptable):
  - Photo Consent – to allow agency and UWBC to take and use photos and video recordings of the individual. This one form is for all Healthy Aging granting streams.
  - Participation Consent – consent to participate in the program including use of data collected for program evaluation purposes.
  - Research Consent – to provide their PHN for research purposes.
    - If providing written consent, program staff will be asked to sign on the last page as well. For the field "Study Role", please write "Higher Needs local site coordinator/staff"

The purpose of this data collection is to strengthen the program and demonstrate its objective impact. This cannot be done without data and the consent of the participants. If consent still cannot be obtained after stressing the importance of data collection, and that the data collected will be anonymized, please follow the steps below.

*Participant does not consent to providing their PHN:

If the participant does not consent to providing you with the PHN that is ok. We recommend trying again at another time once you have established trust, or once you feel they are truly embracing the program. It is possible that once they see and feel the impacts, they will want to help ensure that these programs continue.

If the participant has expressed that they would like to be contacted directly by the UBC research team please write "Contact participant" in the PHN field. Please ensure they provide consent for the research team to contact them. See instructions in the Q&A below.

*Participant refuses to answer some questions in Part I, II or III:

Enter whatever information you can collect. We will also add the option to select “No Answer” when participants choose not to answer.

We understand some questions may be hard to ask, but the questions are all important. The more data we are able to collect the better we will be able to evaluate the effectiveness of the program and advocate for continued funding. Remember, you are not being evaluated at an organizational level, but rather the program as a whole (FFCG, TAPS, SP).

iUnite

If you are transferring data collected from (paper or word doc.) forms using versions prior to April 2021, you will find that some fields do not appear in iUnite as the forms were modified part way through the program. Please ensure you are using the latest intake forms. If you have information on an older version of the Intake form and there is no field in iUnite then you do not have to track this information in iUnite.

If you are NOT using iUnite as your client database (ie. for service tracking), you will have to add basic participant information first (Part I) before you can complete Part II & III questions. Please refer to the iUnite Participant Intake Guide on how to add participants and complete their profile.

- Part I fields that are mandatory for FFCSP/TAPS/SPP programs:
    - Programs
    - First & Last Name
    - DOB
    - Address & Postal Code
    - Living Arrangement
    - Gender
    - Ethnic Origin & Language

Q&A:

Q1) When does a UBC consent form need to be filled out?

When a PHN is provided, please fill out the UBC consent form. If the participant gave consent verbally, please use the verbal consent form (**Appendix B**: HN Verbal Consent Script).

Q2) If "contact participant" is entered into the PHN field, how will the seniors be contacted?

UBC does not have access to participant contact information. The only way a participant could be contacted is if the UBC researcher received this information from the agency.

Q3) What is the process if the UBC research team reaches out to a participant?

If the participant chooses to have the UBC researcher reach out to them directly then they would have to agree to "Future Contact" (see page 6 of **Appendix C**: HN written consent form):

Future Contact
We may conduct other research projects related to the Higher Needs program in the future which may require participant recruitment. May we contact you should these opportunities arise?

- ☐ *Yes. You may contact me in the future regarding other studies.*
- ☐ *No. I do not wish to be contacted for other studies.*

Alternatively, if the participant (or the agency) does not complete this portion of the consent form and would like to be introduced to the researcher at a later date then this would be facilitated by the agency directly.

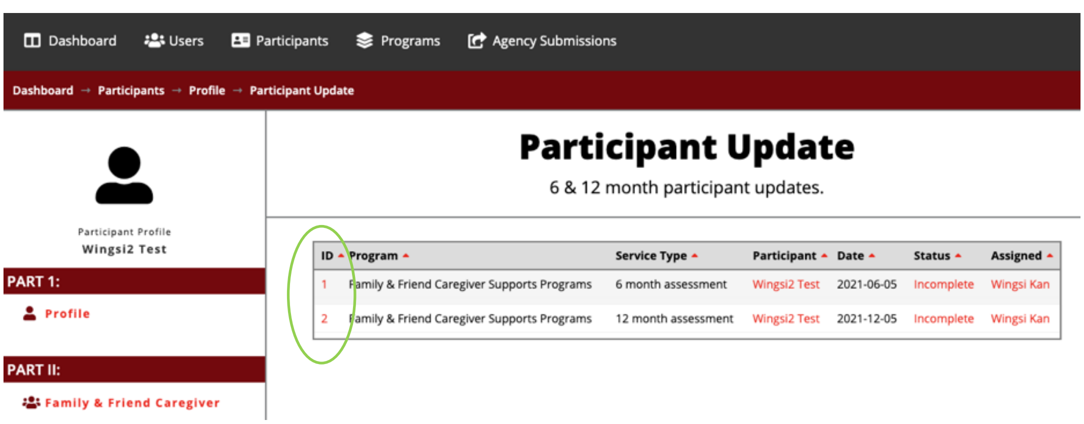
Q4) Rating scales are different on paper and online

The most up-to-date paper forms on CORE have the same rating scale in iUnite. If you have an older form, and find the scales are different, you can choose "n/a" or leave it blank as we want to maintain data integrity. Please keep copies of the paper version as Howegroup may request this information at a later date.

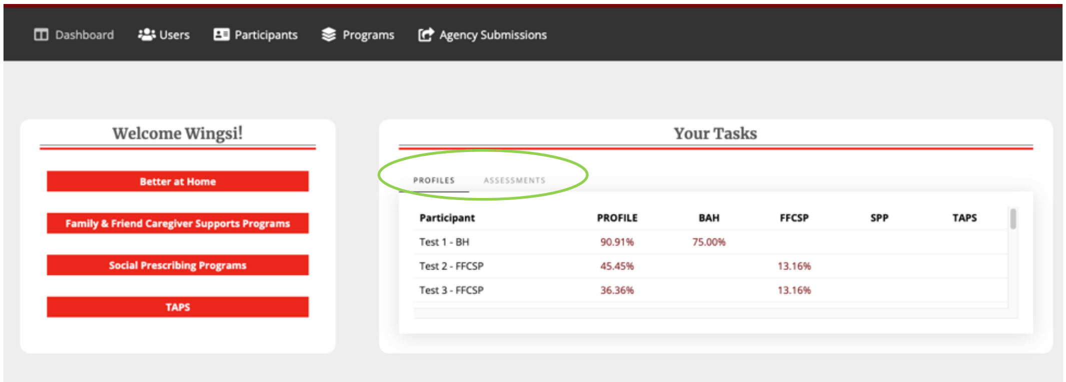
Q5) How to see if a participant's 6/12 month is complete?

Go to participant's profile and click into 'Part III: Participant Update'. You will see the status in the table. Once a profile is completed 100% (all fields in the form have been filled), the status will change to a green "Complete".

Click on the **ID** number in the list to access the form. Fill in fields and remember to click "Submit" at the bottom of the page to save.



Alternatively, you can see "Your Task" in the Dashboard, to see how complete each participant's profile is. There are two tabs in "Your Task" – **Profiles** (for Parts I & II) and **Assessments** (Part III). Click on the percentage to be taken to the participant's page.



Q6) Some participants choose NOT to answer questions in Part II/III, so the status always shows as incomplete.

Not to worry, the data will still be used. Enter what you can. We will also add the option to select "No Answer" when participants choose not to answer.

Inactive participants' data (for example they used the service but stopped using it because they moved away) will still be pulled and included. This may also be the same for a participant that attended your program but has been successful and has moved on to access community supports on their own (which is a good thing).

Q7) Is there a deadline for 6-month & 12-month assessment? If there are participants who are due for 6-month assessment close to the deadline, is the data expected to be uploaded for the upcoming data pull?

The check-in assessments (Part III) should be done 6 months and 12 months from the original intake date. This is just a guideline as it also has to work for you and your participant. For example, if the first check-in is done after 7 months that's ok - what is important is that it is done at some time. If you have not done any check-in assessments please start as soon as you can. Always do the 6-month assessment first and the 12-month assessment second. Please try to capture as many as you can by November 30th which is the first data pull. The second data pull will be March 31, 2022.

If the assessment comes up on or just before Oct 31, 2021, please do your best to enter their info by Nov 30 (in time for first data pull by Howegroup).

Q8) One time referral or "brief service"

You do not need to complete the intake and 6 & 12-month follow up for these individuals. These intakes and forms are for ongoing relationships and to see the change over time. You can fill in Part I – to create a profile in case the participant comes back and you want a record, but they will not be counted as part of the program.

Who to contact if you have further questions:

Tech support – email help@iunite.ca
Data collection – email bobbis@uwbc.ca

United Way British Columbia
4543 Canada Way, Burnaby, BC, V5G 4T4
www.uwlm.ca/your-impact/healthyaging