



Client / Caregiver Registration Package – Client Section

Our Database & Security of Clients' Data

- Our project ...** does not store any data on the internet.
moves “**YOU**” across the internet and helps YOU find OUR privately owned and secure server.
- Client records...** cannot be saved to any computer because we programmed the system not to allow this. There is no risk of anyone other than the registered service providers seeing the files.
- Our database is ...** software which has been specially programmed for ease of use only by **registered service provider**.
- On your screen ...** you will see a copy of the data which has been first **encrypted by our server**, then sent to your computer, **then decoded** by your computer so that you can read it.
the reverse happens when you hit save or submit.
- Our server ...** is physically located in a **secure location** in an undisclosed health institution.
- A server is ...** a metal box (the body) which contains a hard drive (a disc that looks like a very large CD), database software (the brain) which has been put onto the hard drive, and other metal equipment and a few wires.



Client/Substitute Decision Maker/Caregiver - Invitation Letter

Dear Participant:

From November 2001 until September 2002, the Traumatic Brain Injury (TBI) Integration Pilot Project will gather client data to improve coordination and tracking of referrals to care and/or services for clients with a traumatic brain injury. This Project would like your help to improve the Champlain District's rehabilitation referral system so that it can provide:

- A centralized coordination and referral tracking "office" which will track your transfer (for example, leaving hospital to go home) in order to eliminate the gaps that may occur during your transfer.
- Better access to information about brain injury resources.
- Improved communication and coordination between care and services.

Participating in this project is voluntary and there is no cost for you to participate. Your privacy will be protected at all times. **Our database information is not stored on the internet. At no time does any of our data move across the internet.** Your participation means that you are giving "informed consent" and "authorization to release" information about you to health service providers that have "qualified" to participate in this project.

As you near discharge, your health care team and/or private service provider(s) will fill out many forms. Only the data collected on the TBI forms (hard copy and electronic) will be entered into our centralized database which service providers will have access to. This will make your referral(s) easier and faster, and eliminate the number of times you will need to "repeat" your personal history and health information. You or your family will be asked to complete some forms or participate in activities so that your progress is easier to see.

You can quit any time you wish by informing the Clinical Coordinator/Educator (listed below) in writing.

Thank you for helping us to improve the coordination of your rehabilitation and community re-integration. Before we proceed, please be sure to read and sign the attached consent form and return it to your service provider(s).

Project Information:

Beverley Leeks	Project Manager	Tel: (613) 737-7350 ext.5239	Email: bleeks@ottawahospital.on.ca
Elly Nadorp	Clinical Coordinator/Educator	Tel: (613) 737-7350 ext.5243	Email: enadorp@ottawahospital.on.ca
Address:	The Rehabilitation Centre, 505 Smyth Road, Ottawa, ON, K1H 8M2		Fax: (613) 739-3273



Client / Caregiver Agreement to Participate

ALL FIELDS ARE MANDATORY

Client's Name	Last Name	First Name	Gender: <input type="checkbox"/> male <input type="checkbox"/> female
Health Card No:		Date of Birth:	Year / Month / day
Spoken Language (Check all that apply)	<input type="checkbox"/> English <input type="checkbox"/> French <input type="checkbox"/> Other: _____	Preferred Language for Contact Purposes	<input type="checkbox"/> English <input type="checkbox"/> French
Name of Attending Service Provider: _____			
Name of Data Entry Person: _____			

NOTE: BE SURE TO HAVE ALL INITIALS AND SIGNATURES ON BOTH PAGES

I volunteer to participate. I can refuse to participate in, or I can withdraw from the TBI Pilot Project at any time, with no penalty or impact on my future care. The project runs from November 2001 until September 2002. There is no cost for me to participate. I can do this by contacting my service provider(s), or the TBI Clinical Coordinator/Educator.

Client/Substitute Decision Maker's initials _____

I will give **“informed consent”** or **“authorization to release”** information about me to all service providers (working as a team and/or independently) who are involved in my personal care and/or services. I can withdraw my “Authorization for Release of Information” by contacting my service provider(s), or the TBI Clinical Coordinator/Educator at any time.

Client/Substitute Decision Maker's initials _____

When I leave this setting/service, the forms will be sent to the Project Office and the referral destinations I have authorized. Referral destinations will be decided by my service provider and me/substitute decision maker. The Clinical Coordinator/Educator will ensure a smooth transition to my next rehabilitation setting/service. The Project will keep the information, and share this information with my next rehabilitation setting/service.

Client/Substitute Decision Maker's initials _____

After Referral, my information will be placed in a larger database. Any identifying information will be removed in order to maintain my privacy.

NOTE: IF YOU COMPLETED THIS FORM “ON PAPER” ONLY, YOU MUST SEND A COPY (FAX OR MAIL) OF THE KEY IDENTIFIERS (BOX ABOVE) TO THE TBI OFFICE FOR ON-LINE DATA ENTRY, IF YOU ARE NOT ABLE TO DO SO YOURSELF.



Client Agreement to Participate (con't.)

NOTE: BE SURE TO HAVE ALL INITIALS AND SIGNATURES ON BOTH PAGES

My information will be treated with the utmost concern for my privacy and confidentiality because:

- The Project Team members have signed confidentiality agreements
- My personal information will only be used for coordination and referral tracking purposes
- Security measures will be used for electronic and paper file
- My personal information will be coded so that no personal information is shared with the Ministry of Health or with the project team when they study the results
- All personal information not needed for coordination and tracking will be shredded at project end
- Any publication will be using group findings and no personal information about any person in the project will be shared

Client/Substitute Decision Maker's Initials _____

I have been given a copy of the consent, and understand how to reach the Project Manager and/or the Clinical Coordinator/ Educator of the TBI Integration Project if I have any questions or concerns.

Client/Substitute Decision Maker:

print name

signature

Date: ____/____/____
year month day

Relationship if signed by other than the client: _____

Witness:

print name

signature

Date: ____/____/____
year month day