

Toronto ABI Network Data Release Guidelines September, 2005

Background

The Toronto ABI Network's core function is the management of a referral system for people with acquired brain injury as they move within the publicly funded health care system in Toronto. Data for each client who is referred through the ABI Network is gathered. A series of reports are made available to the members of the ABI Network on a monthly and quarterly basis about the number of clients referred, the nature of the clients and their discharge destination points. The data in these reports is presented in aggregate form.

The Toronto ABI Network is able to provide reports with individual client data as per the data fields within the existing database. The Network is also able to eliminate selected fields and alter other fields such as postal code to move in and out of the issue of client confidentiality. The Network is able to prepare data for release with individual member data removed.

Members of the Toronto ABI Network signed five-year Participation Agreements in 2003 that outlined the role of the Network and its members in relation to these requests.

- The agreements outline the organizations responsibility for obtaining consent (See Consent Form attached). The consent form includes the phrase:
*I understand that this information is to be used by the recipient(s) for the purpose of facilitating a referral; for aggregate data use and potentially, for research**
** Summaries of this information may be used to identify trends in use of health services and help answer research questions about brain injury and the course of treatment. No identifying information will be released other than what is needed for placement purposes as specified above.*
- It is the responsibility of the person who completes the referral form and submits to that form to the ABI Network who is responsible for the completion of the consent form and the discussion with the patient regarding the potential use of their personal information in its individual and aggregate forms
- The Participation Agreement outlines the Toronto ABI Network's responsibility to maintain as private all individual client data:
 - *The individual patient information is owned by the patient and will only be used for the purposes outlined in the consent form (see above) and only released to those persons and / or organizations identified in the consent form, in compliance with the existing privacy legislation.*

Guidelines

On occasion, there are requests from individual members of the Network for client data in aggregate form and at the client specific or organization specific level for research purposes. The following guidelines will support decision-making regarding all requests for data release.

1. All requests for data will be accompanied by
 - a. A written request from a member outlining the type of data required, the reason for the data and the anticipated outcome from the project findings.
 - b. A copy of the project proposal
 - c. A copy of ethics approval from a member organization
2. In the event the request for data is based on an aggregate form of the data then:
 - a. The Executive Committee will review the request and approve or deny the request.
 - b. The secretariat will provide the data as requested.
 - c. A cost-recovery fee of \$200.00 will be applied.
 - d. The Advisory Committee will be informed of these requests at regularly scheduled committee meetings.
3. In the event the request for data is at an individual client or organization level or at the member level then:
 - a. The Executive Committee will review the request and determine whether to proceed.
 - b. Data will be made available to the requester at the level that least exposes the client to risk of identification such as the first three digits of the postal code rather than the full six digits.
 - c. The Advisory Committee will be informed of this type of request before it is released.
 - d. The Secretariat will support discussion between member organizations as requested.
 - e. The Network will release only data that has been expressly approved by member organizations.
 - f. The secretariat will provide the data as requested by the member organizations.
 - g. A cost-recovery fee of \$200.00 will be applied.
4. The Executive Committee of the Toronto ABI Network will be the final decision maker with regards to all data requests.