Interactive Symptom Assessment and Collection (ISAAC) Tool

Frequently Asked Privacy Questions for Patients

1. Who should read this document?

Cancer Care Ontario (CCO) has created this set of "frequently asked questions" (FAQs) to give patients and their families information about the services and safeguards CCO employs with respect to our web-based symptom screening tool called Interactive Symptom Assessment and Collection (ISAAC). This tool is provided to participating hospitals and Community Care Access Centres (CCACs).

2. Who is Cancer Care Ontario?

CCO, an agency of the Ontario Ministry of Health and Long-Term Care, is the lead organization in Ontario on matters related to cancer control and cancer services. CCO is the provincial government's principal adviser on cancer issues, with a mission to improve the performance of the cancer system by driving quality, accountability and innovation in all cancer-related services

3. What is ISAAC?

ISAAC is a **web-based symptom screening tool** provided by CCO to health care providers (and their patients, where available) to monitor patients' symptoms. At some hospitals, for example, you may be able to log into ISAAC at a touch screen kiosk and enter information about your symptoms (e.g. my anxiety level is a "3" on a scale of 0 to 10). Your health care provider can view this information and use it adjust your care plan. At other hospitals, your health care provider may enter this information into ISAAC for you. If you are not sure whether your hospital provides patient access to ISAAC, please ask your health care provider. CCO provides ISAAC to participating hospitals and CCACs in its capacity as a "health information network provider" under the Ontario *Personal Health Information Protection Act, 2004*

ISAAC is also used by hospitals and CCACs to disclose cancer-related information to CCO. CCO uses this information to plan, manage, and improve cancer services in the province. CCO is permitted to collect and use this information under its authority as a "prescribed entity" under the Ontario *Personal Health Information Protection Act, 2004*.

4. What type of information is collected via ISAAC and for what purposes?

Your health care provider collects your personal health information via ISAAC to monitor and manage your symptoms. This information may include your name, health card number, symptoms you may be experiencing during your care (e.g. nausea or pain), the facility where you are being treated, and information about the health care provider assessing your symptoms.

You may also be enrolled in ISAAC to enter information about the symptoms you are experiencing (e.g. my pain level is a "4" on a scale of 0 to 10) through a touch screen kiosk or secure internet connection.

CCO collects the same information from health care providers via ISAAC to plan, manage, and improve cancer services in the province.

5. Can I have access to my personal health information in ISAAC?

Yes. You can ask your health care provider for a copy of the personal health information held about you in ISAAC. At some hospitals, you can ask your health care provider to set up your own ISAAC access account. If you are not sure whether your hospital provides patient access to ISAAC, please ask your health care provider.

6. Can I ask a family member or other caregiver to access ISAAC on my behalf?

Yes. Where patient access to ISAAC is available (see Question #5 above), you may choose to have a trusted family member or other caregiver enter information about symptoms you are experiencing. If you choose to do this, your family member or care giver will access ISAAC using your username and password.

7. Who accesses my personal health information and for what purpose?

There are three ways your personal health information may be accessed:

1) By your health care providers;
2) By you, at hospitals where patient access to ISAAC is available; and
3) By a limited number of CCO technical support staff.

Health care providers involved in your care can access your personal health information in ISAAC through a secure website and are only permitted to access information about patients they are treating. This means that a health care provider who is not part of your healthcare team cannot view your ISAAC record.

If **you** are enrolled to use ISAAC, you will be given a username and password, which will permit you access only to your own information through a secure website (via touch screen kiosk or the internet).

CCO technical support staff have access to ISAAC in order to provide information technology (IT) support and to extract information to plan, manage, and improve cancer services in the province. Support staff also have physical access to the ISAAC server, which is securely retained in the CCO data centre.

8. How is my personal health information protected by CCO?

Your personal health information in ISAAC is protected by *administrative*, *technical*, and *physical* safeguards.

- **Administrative Safeguards:** Your health care providers sign agreements to use ISAAC, which require them to keep confidential the personal health information they have access to. CCO staff with access to ISAAC sign a similar agreement, and regularly attend privacy and security training to ensure they understand the safeguards they must employ to protect personal health information.

  CCO also hired an independent privacy consultant to conduct a "privacy impact assessment" (PIA), which examined potential privacy and security risks associated with ISAAC and made recommendations to address these risks. CCO has since implemented all PIA recommendations related to the ISAAC tool.

- **Technical Safeguards**: All ISAAC users - including patients - access ISAAC with a unique username and password and through a secure (i.e. encrypted) website (via touch screen kiosk or the internet).

- **Physical Safeguards**: The ISAAC databases are located in CCO's secure data centre. Access to the data centre is limited to a small number of support staff and controlled by electronic access cards and monitored with video surveillance.

9. How can I help protect the personal health information I enter into ISAAC?

Some hospitals and CCACs have the ability to enroll you in ISAAC so that you can enter information about the symptoms you are experiencing through a touch screen kiosk or secure internet connection. If you have access to ISAAC, you will be required to read and "sign" a Terms of Use the first time you login. This agreement outlines the rules for your appropriate use of ISAAC.

There are a number of additional ways that you can protect your personal health information when you use ISAAC:

- Keep your username and password confidential (i.e. do not share your credentials with others and do not write your password down) unless you have chosen a trusted family member or caregiver to use ISAAC on your behalf (see Question #6 above).
- Always ensure the "padlock" is activated on the computer screen if accessing ISAAC from home (found at the bottom right-hand corner). A closed padlock indicates the website is secure. The padlock will look like this symbol:

- Always log out of ISAAC when you are done entering or viewing information.
- Contact CCO's Privacy Office if you suspect your ISAAC record was accessed by an unauthorized user.

10. Who can I speak to if I have questions about the privacy or security of ISAAC?

If you have questions about the privacy or security of ISAAC, please contact the CCO Privacy Office:

- **Mail**: Cancer Care Ontario, 620 University Avenue, Toronto, Ontario, M5G 2L7
- **Email**: privacyoffice@cancercare.on.ca
- **Phone**: 416-971-9800 ext. 3200