



INFORMATION FOR PATIENTS AND FAMILIES

Helping you work through your ethical issues and concerns



Ethics Consultation Service

This panel features a blue-tinted background image of a group of people, including a woman and a child, smiling and talking. A white triangle in the top-left corner points towards the text.

There are so many care options but which is best for me or my family member?



Patient Experience

This panel features a red-tinted background image of a woman with a stethoscope around her neck talking to another person. A white triangle in the top-left corner points towards the text.

Whom should I talk to about my care experience?



Privacy

This panel features a teal-tinted background image of a doctor with a stethoscope talking to a patient in a hospital bed. A white triangle in the top-left corner points towards the text.

How is my health information being accessed?



Research

This panel features a yellow-tinted background image of a scientist in a lab coat working with laboratory equipment. A white triangle in the top-left corner points towards the text.

What are my rights as a participant in research?

Introduction

Ethics in health care is about stopping to consider the available options and to help you make the best choice for you and your loved ones. It is not just about following rules.

Ethics at HHS involves:

- treating people fairly,
- removing barriers to accessing health services,
- respecting patients' privacy,
- communicating effectively, and
- making sure the hospital is a safe place for all.

At HHS we have a number of people and resources to support patients and families to help make your stay at HHS a positive experience. If you have a question or concern, the first step is to speak with your health care team.

If you find yourself asking one or more of these questions, we have resources to help you work through it.

- Does your question cause moral distress, or involve disagreements, concerns or uncertainties about you or your loved one's care? If yes, please see page 4 for information on the Clinical Ethics Consultation Service. This service helps patients, families and health care teams work through complex and difficult decisions regarding health care needs.
- Do you have a compliment, concern or question about your care, safety or experience? If yes, please see page 5 for information on the Office of Patient Experience. This service works with patients and families to promote an excellent patient and family experience.
- Does your question involve access to or use of your personal health information? If yes, please see page 6 for information on the Privacy and Freedom of Information Office. This service oversees access and restriction of personal health information, as well as access to HHS' business and other records.
- Does your question involve concerns about research? If yes, please see page 7 for information on the Hamilton Integrated Research Ethics Board. This service ensures the safety of research participants.

If you cannot decide which service meets your needs, then you can contact the Ethics Consultation Service by calling paging at 905-521-2100 Ext 73664 and ask for the ethics consultant on call. Or you can send an e-mail to the officeofethics@hhs.ca. This service will help connect you to the right people.

Clinical Ethics Consultation

Facing Difficult Choices

Patients, families, staff, doctors, leaders and trainees make up the health care team. Health care teams make ethical decisions every day in caring for patients. Typical ethical questions include:

- **What** should we do? (What actions are good or right?)
- **Why** should we do it? (Exploring the reasons for our decisions.)
- **How** should the decision be made, and **who** should make it?

Some situations are more complex and require difficult decisions where there are no clear answers. In such cases, **any** member of the health care team, including patients and families, may contact the Clinical Ethics Consultation Service for support.

When should I contact the Clinical Ethics Consultation Service?

Common situations where Ethics Consultants can help include:

- you have a disagreement with your health care team regarding your goals of care
- you are uncertain how to make the best decisions for yourself
- you think the treatment you are receiving is not warranted
- you are asked to make a medical decisions on behalf of another person and are unsure how to fulfil this role
- you feel you are facing an ethical dilemma or conflict with your health care team but are uncertain whom to contact

NOTE: Your social worker who is part of your health care team can also address ethical questions or concerns about difficult or challenging discharge plans.

Ethics Consultants assist the process of making ethical decisions by:

- making clear the patient's goals, values, wishes and best interests
- discussing the facts of the situation with everyone involved to make sure that the issues, choices and likely outcomes are clearly understood
- exploring ethical values, principles, norms, policies, standards and resources
- mediating and resolving conflicts between parties
- providing retrospective debriefing of difficult cases

****Ethics Consultants do not make decisions for others****

Consultations can consist of a simple phone call or a series of meetings, depending on the complexity of the situation. Ethics Consultants respect the privacy of everyone involved, within legal limits.

How do I access the Clinical Ethics Consultation Service?

Call **905-521-2100, ext. 76443**, and ask to page the Ethics Consultant on call. Leave your name and phone number. An Ethics Consultant will call you back within an hour. Ethics Consultation is available Monday to Friday from 8:30 am to 4:30 pm. More information is available at www.hamiltonhealthsciences.ca/ethics or by calling the Office of Ethics at 905-521-2100 ext.73661 or email: officeofethics@hsc.ca

Patient Experience

The Patient Experience Team provides leadership and support throughout Hamilton Health Sciences to promote an excellent patient/family experience. Our office works with patients and families who may have compliments, questions or concerns about the care or service received in hospital.

When should I contact the Office of Patient Experience?

Common situations where the Patient Experience Team can help include:

- you want to share a compliment about your experience
- you want to voice a concern about your care or service
- you have suggestions or ideas to improve your health care experience
- you would like to share feedback on ways to improve overall hospital processes
- you would like to provide advice on addressing patient safety issues
- you need help getting connected with the right person or service

How will the Patient Experience Team help?

- support the communication between the patients/families in order to make sure that patients/families receive the best care and experience possible
- listen to and understand your concerns, and try to help you find a solution
- partner with you to make sure that your patient experience needs are understood
- share your care or service feedback with the right people, for a review and follow up
- ensure your safety concerns are looked after
- bring forward your ideas for improvement related to health services and patient safety

How do I access the Patient Experience Team?

The Patient Experience Team can be reached by calling the main intake line at **905-521-2100, extension 75240** from Monday to Friday, 8:30am to 4:00 pm. The Patient Experience Co-ordinators will take your information and forward this to the appropriate team member.

The team is also available via email at patientexperience@hsc.ca or by mail to:
Hamilton Health Sciences Attention: Patient Experience
100 King Street West
P.O. Box 2000
Hamilton, ON
L8N 3Z5

Privacy Ethics

Hamilton Health Sciences takes its responsibility to protect the privacy of its' patient's personal health information very seriously. The Privacy and Freedom of Information Office oversees this responsibility and is available to answer any questions you might have.

When should I contact the Privacy and Freedom of Information Office?

Some typical privacy situations include:

- you would like to request access or correct information in to your personal health records
- you would like to restrict access to your personal health information
- you suspect someone has accessed your personal health information inappropriately
- you would like to know if you can access information about HHS' business or other records

How do I contact the Privacy and Freedom of Information Office team members?

Details regarding Privacy and Freedom of Information, HHS policy and procedures, answers to Frequently Asked Questions and education resources, are available at: <http://www.hamiltonhealthsciences.ca/body.cfm?id=1759>

The Privacy and Freedom of Information Office can be reached by calling our main line at **905-521-2100 extension 75122 (Privacy) or 75126 (Freedom of Information)** from Monday-Friday 8:30 am to 4:00 pm or via email at privacy@hpsc.ca and FOI@hpsc.ca

Note: Please do not email personal health information to or from external email addresses.

Research Ethics

Health care research may involve not just hospitalized patients, but also people seen in outpatient clinics and programs, their families and caregivers, as well as university students, children, hospital volunteers, and people in the general community. Research on humans cannot take place without it being reviewed and considered safe by a group of people who are trained and experienced to do so.

The Hamilton Integrated Research Ethics Board (HiREB) is a subcommittee of the Hospitals' Medical Advisory Committee and is a jointly constituted board of St. Joseph's Healthcare Hamilton, Hamilton Health Sciences and McMaster University's Faculty of Health Sciences. It is committed to protecting research participants by making sure that all research involving humans is both scientifically valid and ethically sound. *Our mandate is to safeguard the rights, safety and well-being of all research participants.* HiREB operates under the principles of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2), and the International Conference on Harmonization: Good Clinical Practice (ICH GCP).

What does the HiREB do?

All research projects involving McMaster University, St. Joseph's Healthcare Hamilton and Hamilton Health Sciences physicians, staff, students, or patients, must get ethical approval from the HiREB before the research can begin. The HiREB reviews and approves research projects, making sure that they meet acceptable ethical and scientific standards. The HiREB also provides advice on the ethical, scientific and technical aspects of planning research projects. Further information on Research Ethics and the HiREB is available at:

www.HIREB.ca

When do I contact the HiREB?

Common situations where the research ethics board can help include:

- You feel the study you are participating in is unsafe
- You would like to withdraw from a study you are participating in
- You have questions or concerns regarding a study you are participating in but are afraid to ask the research team
- You don't understand the study you are participating in and are having difficulty finding the answers

How do I access Chair of HiREB Research?

For questions about patient rights as a research participant, please contact the Office of the Chair of HiREB and can be reached by calling the main intake line at **905-521-2100, extension 42013** from Monday to Friday, 8:30am to 4:00 pm. or by mail to:

293 Wellington Street North, Suite 102
Hamilton, Ontario
L8L 8E7

This information is also included on the Information & Consent form given to research participants during the consenting process.

Educational Material for Patients and Families

HHS has many patient education materials related to issues frequently encountered in health care. They are available through our HHS internet site and also by clicking on the link below:

[Ethics Consultation Service brochure](#)

[Family Presence / Visiting FAQ](#)

[Making your wishes known. Goals of Care pamphlet](#)

[Making decisions for others. Your role as a Substitute Decision Maker](#)

[Mutual Respect Handbook](#)

[Palliative Care at Hamilton Health Sciences and Surrounding Areas](#)

[Resources at Hamilton Health Sciences to Address Ethical Issues](#)