

Guidelines for the Post-Discharge Contact of Patients Research Ethics Board

The St. Joseph's Health Centre REB has developed a guideline to assist staff in understanding the circumstances under which patients may be contacted after discharge from the hospital. There are three circumstances where this may occur: (a) as part of the patient's circle of care, (b) for quality improvement purposes, and (c) for the purposes of research (REB approval is required).

The three circumstances are detailed below. Please see which category your purpose for contacting the patient falls under and follow the guidelines.

1. You wish to contact a patient related to the patient's health care.

If you are a health information custodian (HIC)¹ and the reason you would like to contact a patient and the purpose of contact is directly related to their health care² (ie. not research, marketing, etc), this is allowable as it is

¹ A Health Information Custodian is a person or organization described in PHIPA with custody or control of personal health information (PHI) as a result of, or in connection with, the performance of its powers, duties or work. Health Information Custodians include health care practitioners, hospitals, pharmacies, laboratories, etc. PHIPA defines a health care practitioner as a person who is a member within the meaning of the *Regulated health Professions Act, 1991*, who provides health care; a person registered as a drugless practitioner under the Drugless Practitioners Act who provides health care; a social worker who provides health care and any other person whose primary function is to provide health care for payment (e.g. doctors, nurses, dieticians, pharmacists, etc.).

Custodians may have **agents**, which PHIPA defines as a person that, with the authorization of the custodian, acts for or on behalf of the custodian in respect of PHI for the purposes of the custodian and not the agent's own purposes. Providing PHI between a custodian and an agent is considered to be a use by the custodian, and is not viewed as a disclosure by the person providing the information, nor as a collection by the person to whom the information is provided. A custodian may not disclose PHI to a non-custodian unless the individual has given express consent, or if the disclosure is permitted or required by PHIPA, or by another law. (Circle of Care. Sharing Personal Health Information for Health Care Purposes. Ann Cavoukian, Ph.D. Information and Privacy Commissioner, Ontario, Canada.)

² PHIPA defines **health care** as any observation, examination, assessment, care, service or procedure that is done for a health-related purpose and that is carried out or provided. (Fact Sheet Number 11, February 2006. Health Information Custodians Working for Non-Health Information Custodians. Ann Cavoukian, Ph.D. Information and Privacy Commissioner, Ontario, Canada.)

considered continuity of care; however, prior to contacting patients, please ensure you are authorized to do so through your supervisor/manager.

The term “circle of care” is commonly used to describe the ability of certain health information custodians to assume an individual’s implied consent to collect, use or disclose personal health information for the purpose of providing health care.”³ Under these circumstances, REB approval is not required. (Please see Appendix A for more details.)

2. You wish to contact patients to involve them in a quality improvement (QI) initiative.

- Definition of QI: Quality Improvement is “an activity where the primary purpose is to monitor, evaluate or improve the quality of health care⁴ delivered by a health care provider (an individual, a service or an organization).”⁵
- Some quality initiatives may require REB approval, whereby the consent process for contact would be reviewed. (If you are unsure whether your project requires REB approval, please contact the REB coordinator at santost@stjoe.on.ca).
- Prior to contacting patients, Meditech must be checked to determine whether patients have requested they not be contacted for research or surveys.
- If patient involvement is anticipated in your QI plan, best practice is to obtain *explicit consent* (while the patient is in-hospital) to be contacted in the future for the QI initiative. This may be done in-hospital using various methods: involving QI team members, volunteers, students, or a box for patients to provide written consent. Upon contact, consent is immediately re-confirmed before proceeding.
- In the absence of in-hospital consent from the patient, consent to have the discussion about participating in your QI project must be obtained immediately upon next contact (after Meditech has been checked). Consent to participate in the QI project is then obtained upon describing it to the potential participant.
- Scripts for the discussion with the patient should be developed. Scripts should state at the beginning that the interviewer will not be able to

³ Circle of Care. Sharing Personal Health Information for Health Care Purposes. Ann Cavoukian, Ph.D. Information and Privacy Commissioner, Ontario, Canada.

⁴ The “quality of health care” has been modeled in various ways. For example, the [Donabedian model](http://www.hrsa.gov/healthit/toolbox/HealthITAdoptiontoolbox/QualityImprovement/whatisqi.html) includes three dimensions: 1) the structure, which represents the attributes of settings where care is delivered; 2) the process, or whether or not good medical practices are followed; and 3) the outcome, which is the impact of the care on health status. <http://www.hrsa.gov/healthit/toolbox/HealthITAdoptiontoolbox/QualityImprovement/whatisqi.html> Improving the quality of health care therefore could involve improvements in any or all of these dimensions.

⁵ When does quality assurance in health care require independent ethical review? National Health & Medical Research Council, Endorsed 20 February 2003, Australia.

address any health care concerns, and the patient must seek care through their family doctor or the emergency department.

- For assistance in your QI initiative, you may refer to the SJHC Quality Improvement Guide – Guidance for Teams Embarking on a Change Program (<http://sjhcweb.ca/intranet/patientsafety/quality/index.php>).

3. You wish to contact patients to involve them in a research project.

- Contacting patients for research projects does not fall under their circle of care and requires REB approval, whether post-discharge or at other times. Please go to the REB webpage found at <http://www.stjoe.on.ca/education/research/ethicsboard.php> for more information about the REB submission process. You may also contact the REB coordinator at santost@stjoe.on.ca if you have any questions.
- Consent process: explicit consent needs to be obtained from the patient (opt-in), but the appropriateness of the consent process plan will be reviewed by the REB
- Prior to contacting patients, Meditech must be checked to determine whether patients have requested that they not be contacted for research or surveys.

Appendix A

In 2009, Ontario's Information and Privacy Commissioner, Dr. Ann Cavoukian, released the publication - *Circle of Care: Sharing Personal Health Information for Health-Care Purposes* - that includes specific practical examples to help clarify when health information custodians can assume a patient's *implied* consent to collect, use or disclose personal health information (PHI).

There are six conditions that must be satisfied before a health information custodian may assume implied consent to collect, use or disclose PHI:

- (a) The health information custodian must fall within a category of health information custodians that are entitled to rely on assumed implied consent.
- (b) The PHI to be collected, used or disclosed by the health information custodian must have been received from the individual, his or her substitute decision-maker or another health information custodian.
- (c) The health information custodian must have received the PHI that is being collected, used or disclosed for the purpose of providing or assisting in the provision of health care to the individual.
- (d) The purpose of the collection, use or disclosure of PHI by the health information custodian must be for the provision of health care or assisting in the provision of health care to the individual.
- (e) In the context of disclosure, the disclosure of PHI by the health information custodian must be to another health information custodian.
- (f) The health information custodian that receives the PHI must not be aware that the individual has expressly withheld or withdrawn his or her consent to the collection, use or disclosure (ie. this involves patients that do not want their PHI disclosed outside what is reasonably necessary for the provision of their care).⁶

For further clarification please refer to the Circle of Care document which may be found on the internet (<http://www.ipc.on.ca/images/Resources/circle-care.pdf>).

⁶ Circle of Care. Sharing Personal Health Information for Health Care Purposes. Ann Cavoukian, Ph.D. Information and Privacy Commissioner, Ontario, Canada.