DISCLOSING PERSONAL HEALTH INFORMATION TO THIRD PARTIES

DISCLOSURE TO FAMILY MEMBERS AND SURROGATES

CASE STUDY 1 - DISCLOSURE TO FAMILY MEMBERS

An elderly Asian woman, Mrs. Y, who has a large, extended family, is admitted to the critical care unit requiring confirmatory (diagnostic) tests. The hospitalist assigned to treat her is confronted by her eldest son who asks to speak to him in the hall. He informs the hospitalist that, in their tradition, the head of the family (him) makes all decisions. He asks that Mrs. Y not be told her diagnosis and that he be consulted. He explains that he will make all decisions based on the information the hospitalist provides. The situation is complicated by the fact that Mrs. Y has limited command of English.

QUESTIONS

PART ONE
1. Should the hospitalist honour the son’s request?
2. Does the hospitalist have explicit consent from Mrs. Y to disclose PHI to her son?
3. Would honouring the son’s request breach her privacy and break the hospitalist’s pledge of confidentiality?

PART TWO
1. Should the hospitalist assume that he may disclose Mrs. Y’s diagnosis and treatment plan to her other family members?

PART ONE DISCUSSION

The son’s request to be consulted and make health care decisions entails disclosing Mrs. Y’s PHI to him. However, paragraph 31 of the CMA’s Code of Ethics dictates: “Protect the personal health information of your patients.” Principle 2 of the Principles for the Protection of Patients’ Personal Health Information (privacy principles) states: “Patients have a general right to control the use and further disclosure of their personal health information, and a right of reasonable access to the information contained in their medical record.”

Before Mrs. Y’s PHI is disclosed to the son and before the hospitalist acquiesces to his request to be the sole decision-maker, more information is required. First, the hospitalist must establish that Mrs. Y adheres to tradition and, even so, does she want to defer decision-making to her son? Does she wish to recognize her son has her surrogate decision-maker? Second, does Mrs. Y want to know her diagnosis and treatment options? How likely is it that Mrs. Y will be able to infer a general diagnosis from the tests, e.g., biopsies are conducted to confirm cancer. The 5th principle of a therapeutic relationship in the Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care states: “The competent person must be involved in decisions regarding his or her care.”

Deferring decision-making to her son does not negate Mrs. Y’s right to know her health status. These questions can only be answered by determining her preferences. As her command of English is
limited, it is best to engage a professional translator; a family member should not be relied on to translate.

Paragraph 22 of the Code of Ethics states: “Make every reasonable effort to communicate with your patients in such a way that information exchanged is understood.”

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| 1. Should the hospitalist honour the son’s request?  
  The answer depends on Mrs. Y’s directives. If, when asked about her preferences, she defers decision-making and states she does not wish the physician to disclose her diagnosis or treatment plan to her, then, yes, the physician should honour the son’s request.  
  2. Does the hospitalist have explicit consent from the patient to disclose her PHI to a third party?  
  This depends on her answers to the hospitalist’s questions and her directives. If she defers decision-making to her son and understands that he needs all the relevant information to make informed choices, then she grants her son explicit consent to disclose her PHI. Effectively, he becomes her surrogate decision-maker.  
  3. Would honouring the son’s request breach her privacy and break the hospitalist’s pledge of confidentiality?  
  If Mrs. Y defers decision-making to her son, there is no breach of privacy or confidentiality. |

**PART TWO DISCUSSION**

Paragraph 33 of the Code of Ethics advises: “Be aware of your patient’s rights with respect to the collection, use, disclosure and access to their personal health information; ensure that such information is recorded accurately.” Paragraph 35 stipulates: “Disclose your patients’ personal health information to third parties only with their consent, or as provided for by law.”

Paragraph 2 of the Code of Ethics stipulates: “Practise the profession of medicine in a manner that treats the patient with dignity and as a person worthy of respect.”

If Mrs. Y defers decision-making to her son, then the hospitalist follows the wishes of a capable adult. If she does not defer and the hospitalist enables Mrs. Y to make decisions, he follows the directives of his patient, whose well-being should be his primary concern.

However, difficulties may arise. Depending on family dynamics, it might be best to conduct a family meeting, with Mrs. Y’s consent and her attendance. A family meeting can be a supportive environment that enables Mrs. Y to express her wishes. The physician can address concerns or, assuming the services are available, rely on a social worker or an ethicist. Patients’ right to control access to and dissemination of their PHI and the legal requirement to obtain informed consent could be discussed. How much and with whom Mrs. Y wants to share her PHI can be determined; if the family is to provide support (especially on discharge), they may need access to some PHI. Employing a rights-based approach may forestall accusations of cultural insensitivity and limit family discord.
Principle 3 of the privacy principles dictates: “Physicians must handle personal health information in compliance with the applicable federal and provincial privacy laws and professional regulations.”

**Answers**

**PART TWO**

1. Should the hospitalist assume that he may disclose Mrs. Y’s diagnosis and treatment plan to her extended family?

   Deferring decision-making to her son does not entail disclosing her PHI to any other family members. Before disclosing Mrs. Y’s diagnosis and treatment plan to other family members, the hospitalist should seek Mrs. Y’s permission or, if her son is her surrogate decision-maker, his permission. Disclosing PHI to other family members without Mrs. Y’s or her surrogate’s consent constitutes a breach of confidentiality.

**Case Study 2 - Mature Minor and Parent’s “Right to Know”**

Cheryl, a 15-year-old, visits her family physician, who has been treating her since infancy, to request contraceptives. The norm is for 15-year-olds to be seen alone; thus, no parent attends the appointment. The discussion with Cheryl demonstrates that she has the capacity to make this decision. Although she has not yet engaged in sexual activity, she recognizes that her relationship with her boyfriend may soon include sex and she wants to be prepared. She understands the risks and the benefits and recognizes the need to use condoms, i.e., practice safe sex, to mitigate the risk of contracting a sexually transmitted disease. She states that she does not want her parents to know she is on the pill for contraceptive reasons.

Three months later, the physician receives a call from Cheryl’s father. He found Cheryl’s prescription and is angry that he was not consulted or informed of the decision to prescribe the pill to his daughter. He demands to know if Cheryl is taking the pill to regulate her period or for contraception.

**Questions**

1. Should the physician prescribe the pill to Cheryl?
2. Does the physician have an obligation to discuss Cheryl’s request with her parents or guardian before prescribing contraception for her?
3. Does the physician have Cheryl’s consent or should she infer her consent to share her PHI with her parents?
4. Should the physician tell Cheryl’s father that she was prescribed the pill to regulate her menstrual cycle, not as a contraceptive?

**Discussion**

For adults, capacity and competence are assumed. However, people may have the capacity to make one choice but not others. The higher the risk of injury or death, the more robust must be an assessment of capacity. Some jurisdictions stipulate a specific age at which minors may be considered
to be mature minors; others do not. Physicians should know the laws and regulations of their jurisdiction, as mature minors may make medical decisions. The “sliding scale” capacity assessment is also applicable to minors who are approaching the age of consent.

Some jurisdictions allow minors to consent to reproductive and mental health treatments. However, it is wise to disclose to the minor (mature or otherwise) when it may be necessary for the physician to break confidentiality. Limits are always placed on a pledge of confidentiality, e.g., imminent risk of serious harm to a specific identifiable person. During this discussion, the physician can assess whether to advise the minor to disclose his or her care, treatment and/or condition to his or her parent(s) or guardian.

Parents/guardians have the right to make medical decisions on behalf of minors, and this necessitates access to the minors’ PHI. Once minors are assessed as having capacity to make medical decisions (mature minors), they have the right to control access to the health information related to that decision. This can complicate minors’ and physicians’ relations with parents/guardians.

Paragraph 31 of the Code of Ethics stipulates: “Protect the personal health information of your patients.”

Principle 2 of the privacy principles states: “Patients have a general right to control the use and further disclosure of their personal health information, and a right of reasonable access to the information contained in their medical record.”

In the commentary section it is noted: “There are circumstances when a physician must consider whether it is the parent or the child who should have control of personal health information. A young person who is deemed to understand fully the implications of a medical decision is generally also deemed to have control over their personal health information.”

Paragraph 25 of the Code of Ethics states: “Recognize the need to balance the developing competency of minors and the role of families in medical decision-making. Respect the autonomy of those minors who are authorized to consent to treatment.” See also Principle 9 in the Principles of the Therapeutic Relationship section of the Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care. The joint statement outlines 17 principles of a good therapeutic relationship.

Discussing with her father Cheryl’s status as a mature minor, her rights, assessments used to determine capacity to make medical decisions and how her maturity reflects positively on his parenting skills may help diffuse his anger. Although telling him the pill was prescribed to regulate Cheryl’s menstrual cycle would be an “easy way out,” it is inadvisable, as it could damage the patient–doctor relationship. If he discovers the truth, he will know the physician lied to him and he may no longer trust her. A better course of action may be for the physician to say she cannot answer this question because it would breach confidentiality.

**ANSWERS**

1. Should the physician prescribe the pill to Cheryl?
   
   **If the physician assessed Cheryl as having the capacity to make this medical decision and if the pill is medically appropriate, then she may prescribe.**

2. Does the physician have an obligation to discuss Cheryl’s request with
her parents or guardian before prescribing contraception for her?

Usually, if a patient is a mature minor, parents or guardian need not be consulted. However, various jurisdictions have legislation or regulations addressing mature minors and their right to make medical decisions, and physicians should know the law/regulations in their area. Because Cheryl still lives at home, the likelihood of her parents discovering that she is taking the pill is high. Thus advising her to tell her parents and discussing why she does not wish to disclose the information could be beneficial.

3. Does the physician have Cheryl’s consent or should she infer her consent to share her PHI with her parents?

Under these specific circumstances, no, because Cheryl is a mature minor and she specifically stated she did not want her parents to know.

4. Should the physician tell Cheryl’s father that she was prescribed the pill to regulate her menstrual cycle, not as a contraceptive?

While telling a “white lie” may defuse the situation, it may also cause more harm than good. If Cheryl’s father discovers the truth, the physician’s veracity and relationship with him may be damaged.

CASE STUDY 3 - DISCLOSURES TO A SURROGATE/GUARDIAN

A gerontologist provides medical care at a long-term care facility. As a result of a fall, Mrs. G, a 72-year-old widow who lives at the facility, now has cognitive deficits and, because of a broken jaw, she has difficulty chewing and swallowing. It is not yet known whether her cognitive deficits are transient or permanent. A dietician was consulted and believes that, to maintain nutritional sufficiency, a peg tube should be inserted. This requires transfer to a hospital.

For the last two years, Mrs. G has been in a relationship with another resident, Mr. B. Six months ago Mr. B and Mrs. G were diagnosed with syphilis and received treatment.

Her two children were not consulted when Mrs. G’s original plan of care was developed, nor are they aware of the sexually transmitted infection (STI). Mrs. G does not have an advance directive nor did she appoint a durable power of attorney for health care decisions. Mrs. G told the gerontologist that Rory, her son, while having honourable intentions, can be overprotective and controlling; therefore, she has not told Rory or Jean (her daughter) about her relationship with Mr. B.

Both children are willing and able to assist with decision-making and have asked to see their mother’s medical record. On hearing of his mother’s fall, Rory questioned whether the facility was negligent. If access to the full record is granted, Rory and Jean will discover that Mrs. G was treated for an STI, infer that she was or is having a sexual relationship and will likely demand to know with whom.

QUESTIONS

1. Should the children have complete access to Mrs. G’s medical record?
2. If not, should some PHI be disclosed to them?
3. What and how should Mrs. G’s PHI be disclosed to her children?
4. What form of consent is the gerontologist relying on to disclose Mrs.
G’s PHI?
5. Should surrogates be considered part of the circle of care?

**DISCUSSION**

Paragraph 29 of the Code of Ethics states: “When the intentions of an incompetent patient are unknown and when no formal mechanism for making treatment decisions is in place, render such treatment as you believe to be in accordance with the patient’s values or, if these are unknown, the patient’s best interests.”

Because Mrs. G has cognitive deficits and has, at least temporarily, lost the capacity to make medical decisions, a surrogate decision-maker should be consulted. In the absence of a durable power of attorney for health care, most jurisdictions have established a hierarchy of surrogates. Adult children usually fall second on the list, after the spouse. First-order family members are consulted as they are most likely to know the incapacitated patient’s values and belief system. As Mrs. G is a widow and her relationship with Mr. B does not constitute marriage, her children should be consulted about placing the peg tube and the implications, e.g., transfer to hospital.

Paragraph 30 of the Code of Ethics states: “Be considerate of the patient’s family and significant others and cooperate with them in the patient’s interest.”

Some may consider Mr. B a significant other, but, in this case, Mr. B’s and Mrs. G’s relationship is not such that Mr. B should be consulted in developing a care plan; if he was consulted, Mrs. G’s children would, by necessity, discover the relationship. However, Mr. B could be informed that an accident has occurred and, thus, that Mrs. G’s normal routine has been affected.

To make informed decisions, adequate information is required. What constitutes adequate disclosure for medical decision-making does not change depending on who the decision-maker is, the patient or a surrogate. Surrogates need access to all relevant information to make informed choices. Therefore, the information that Mrs. G’s surrogates (her children) need to decide what would be in her best interests should be disclosed to them.

Paragraph 21 of the Code of Ethics states: “Provide your patients with the information they need to make informed decisions about their medical care, and answer their questions to the best of your ability.” See also Principles 1, 7 and 10 of the Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care.

Disclosing adequate information for surrogates to make informed decisions does not mean granting access to the full medical record. Principle 8 of the privacy principles stipulates, “The use or disclosure of patient information within the ‘circle of care’ should be done solely on a need-to-know basis.” Surrogates replace the patient at the centre of the circle of care as they grant consent on behalf of incapacitated patients. Just as with the care team, information should be disclosed to surrogates on a need-to-know basis.

Surrogates assist the care team in providing therapeutic benefits to the patient. Therefore, in the case of an incapacitated person, one may rely on the patient’s implied consent to disclose pertinent PHI. Therefore, Principle 6 of the privacy principles applies: “Under certain circumstances, physicians may rely on a patient’s implied informed consent to share personal health information.” The caveat found in the commentary segment also applies: “Thus a physician may infer consent to… (b) share the necessary personal health information with the appropriate members of the health care team.”
Because Mrs. G told the gerontologist that she has not informed her children of her relationship with Mr. B, one assumes she did not tell them about being treated for an STI. Mrs. G’s history of an STI and who transmitted it is information she does not want Rory and Jean to know. Therefore, to protect Mrs. G’s privacy, access to her entire record should not be granted. Paragraph 28 of the Code of Ethics stipulates: “Respect the intentions of an incompetent patient as they were expressed (e.g., through a valid advance directive or proxy designation) before the patient became incompetent.” Mrs. G specifically told the gerontologist she did not want her children to know about her relationship and one assumes this would apply to all the sequelae.

If access to the entire record is simply denied without explanation, Rory and Jean may become suspicious. They may come to believe that the facility is trying to protect itself from a lawsuit, i.e., access is denied as part of a cover-up. One may wish to consult with the Canadian Medical Protective Association (CMPA) in this regard.

The question remains, how much information should be disclosed to Mrs. G’s children? The portions of her health record relevant to the decision about whether to insert a peg tube and her head and jaw injury should be copied and given to the children. The fact that only portions of her record will be disclosed should be discussed with them. Paragraphs 31 and 37 of the Code of Ethics (therapeutic privilege) may be invoked:

31. Protect the personal health information of your patients.
37. Upon a patient’s request, provide the patient or a third party with a copy of his or her medical record, unless there is a compelling reason to believe that information contained in the record will result in substantial harm to the patient or others.

In addition, although included in the commentary following Principle 9 of the privacy principles, the recommendation that “Physicians must limit the personal health information that is disclosed to only that information which is necessary to fulfill the requirement” should be followed. The portion of Mrs. G’s record preceding her fall and the section following it should be sufficient to allay suspicions, allow the children to determine whether the facility was negligent and facilitate their decision-making, i.e., consent or refusal to insert a peg tube, but consulting with the CMPA could confirm this assumption.

**Answers**

1. Should the children have complete access to Mrs. G’s medical record?
   
   In most cases, only the segments of the record relevant to decision-making should be shared.

2. If not, should some PHI be disclosed to them?
   
   Surrogates require information to make informed choices.

3. What and how should Mrs. G’s PHI be disclosed to her children?
   
   The information they need to make current and, if necessary, ongoing health care decisions should be disclosed to them. If a past medical condition is not relevant to a current or future decision, it should not be disclosed. Because the children requested access to Mrs. G’s health record, the relevant portions should be copied and given to them.

4. What form of consent is the gerontologist relying on to disclose Mrs. G’s PHI?
   
   The form of consent relied on is implied consent.
5. Should surrogates be considered part of the circle of care?
   If they assist with or must make health care decisions, then one should consider them members of the circle of care, as they replace the patient at the centre of the circle.

Health System Usage, Disclosure and Privacy Breaches

Case Study 1 - Disclosure for Billing Purposes

A family physician with a busy, long-established rural practice is in a jurisdiction functioning with an electronic fee-for-service billing system. A patient, Mr. C, comes to her office complaining that “coffee row” is discussing his HIV infection. Mr. C is angry that his health history has become common knowledge. He claims that, according to his information, Ms. X is the person who disclosed his health status. He is angry and demands to know how and why his family physician (or someone from her office) disclosed his HIV status to Ms. X. Ms. X works for the Ministry of Health (MOH) processing billing information.

Questions

1. Can physicians absolutely guarantee PHI will remain private?
2. Is reporting PHI, without explicit prior consent, for billing purposes considered a breach of privacy, breaking confidentiality or unethical?
3. If it is considered a breach, what justifies the current practice of disclosing PHI for billing purposes?
4. Is using PHI for billing purposes a primary or secondary purpose?
5. Should the MOH and, by association, its employees be considered members of the circle of care?
6. Did Ms. X, the MOH employee, breach privacy and contravene her duties or obligations?

Discussion

Paragraph 34 of CMA’s Code of Ethics states: “Avoid public discussions or comments about patients that could reasonably be seen as revealing confidential or identifying information.”

Principle 13 of CMA’s privacy principles states: “Patients should be informed that the treating physician cannot control access or guarantee confidentiality of an electronic health record (EHR) system.”

In this instance, the “leak” did not happen as a result of uploading PHI to an EHR, nor because the physician or her staff discussed the patient’s health in public. Someone unrelated to the physician’s office was the source of the leak. In this instance, the disclosure to the MOH and Ms. X was a legitimate disclosure to a third party.
Principle 4 of the CMA’s privacy principles asserts: “Physicians play an important role in educating patients about possible consensual and non-consensual uses and disclosures that may be made with their personal health information.” In this instance, the physician’s office disclosed the patient’s PHI to the MOH to receive payment for services rendered. The follow-up commentary to Principle 4 advises, “Prior to the collection of health information, the patient should be informed through means such as websites, letters, posters, flyers or conversations that their personal health information… will be used to obtain payment for the health services provided.”

The preamble to the privacy principles recognizes that, once information is collected and shared with a third party, the physician no longer controls access or subsequent disclosures. “With the advent of shared electronic records the physician may not be the custodian of — i.e., control access to — the patient’s records once the health information is collected. The principles therefore recognize that physicians’ responsibilities as data stewards and custodians of health information must be assessed in the light of this framework. Where the term physician is used, it is meant to refer to the custodian of the medical record which in the case of institutions may not be the treating physician.”

The commentary following Principle 13 of the privacy principles notes, “Where possible, personal health information contained in an EHR should be de-identified before it is used for secondary purposes, such as health-system planning.” Identifiable information is disclosed for billing purposes.

That Ms. X linked billing records to an identifiable individual and subsequently disclosed PHI to others suggests she breached MOH’s policies and protocols. Principle 5 of the privacy principles may be invoked to outline the MOH’s obligations regarding PHI: “Security safeguards must be in place to protect personal health information in order to ensure that only authorized collection, use, disclosure or access occurs.” Unauthorized uses can be monitored by “including an access audit ‘trail’ to safeguard against unauthorized access. Patients should be able to access this audit trail.”

This case study demonstrates the shortcomings of an audit trail. Ms. X was authorized to access PHI; she chose to breach confidentiality by contravening paragraph 34 of the CMA’s Code of Ethics. However, Ms. X is not a physician and, thus, is not subject to the code. She is, however, subject to provincial privacy laws. Mr. C may contact the provincial privacy commissioner and/or the MOH to lay a formal complaint against Ms. X and Mr. C should be made aware of this option.

### ANSWERS

1. Can physicians absolutely guarantee PHI will remain private?
   
   Once PHI is shared with third parties, physicians cannot guarantee it will remain private. Physicians can only control their own and monitor their staff’s behaviour. The best a physician can do is promise to keep PHI in their control confidential in compliance with legal exemptions and ethical dictates, train staff about their duty to keep PHI confidential and implement safeguards to monitor access and disclosure.

2. Is reporting PHI, without explicit prior consent, for billing purposes considered a breach of privacy, breaking confidentiality or unethical?
   
   This depends on the promise made to patients. If patients are not informed of limitations and physicians’ privilege to use PHI for secondary purposes, then conceptually, yes it would be a breach. If patients are unaware and uninformed of exemptions, they may believe that only they may waive the duty to keep their PHI confidential; they may believe that
physicians’ duty to keep PHI confidential is absolute. Patients should be informed that physicians have legislated, mandated and regulated privileges that allow them to break confidence for some secondary purposes. As, in this vignette, the disclosures are legislated or regulated, some do not consider this type of disclosure a breach of confidentiality. However, conceptually, it is if the patient disclosed his or her PHI under the assumption that only he or she could grant waivers. The Privacy Wizard is available to help physicians develop tools to inform patients of physicians’ privacy practices.

3. If it is considered a breach, what justifies the current practice of disclosing PHI for billing purposes?
   Pragmatism, implied consent or legislation justifies current practices. Pragmatism, as soliciting explicit prior consent from each patient for each billing cycle is burdensome. Implied consent enables current practice, as one infers that patients understand that if they do not pay at point-of-service, physicians submit bills to health insurers. Legislation and regulations also permit the current practice of disclosing PHI for billing purposes.

4. Is using PHI for billing purposes a primary or secondary purpose?
   It is a secondary purpose, as PHI is not being disclosed to provide direct care or treatment (although the information was collected in the process of providing direct care or treatment).

5. Should the MOH and, by association, its employees be considered members of the circle of care?
   No. The privacy principles define the circle of care as those members of the health care team directly involved in the clinical care and management of the patient.

6. Did Ms. X, the MOH employee, breach privacy and contravene employees’ duties or obligations?
   Yes, PHI is governed by various provincial or federal privacy laws. Usually the laws stipulate that PHI is to remain confidential (subject to legislated exemptions). Reporting HIV status is a legislated exemption, as HIV is a reportable STI, but to whom it is reported is regulated. Disclosing (gossiping about) someone’s HIV status to friends and family is not a legislated exemption.

CASE STUDY 2 - INSURER’S QUALITY ASSURANCE STUDIES, IDENTIFIABLE, DE-IDENTIFIED AND ANONYMISED INFORMATION

A provincial government is studying “best practices” for dialysis. The study has both quantitative and qualitative components, which require direct input from patients. The health ministry “mined” and “matched” its data banks to identify potential recruits. A patient receives a letter from a researcher on behalf of the MOH inviting her to participate in a study because she is on dialysis. The researcher wants to recruit her into the qualitative arm of the study and share her experiences with dialysis. She contacts her physician’s office angry because she believes he shared identifiable PHI with the government and researchers without her explicit prior consent.
QUESTIONS

1. Should the MOH and, by association, its employees be considered members of the circle of care?
2. Are the data being used for health system planning or research?
3. Is this a quality-assurance study?
4. Should this be considered a primary or a secondary purpose?
5. Does the government have the right to mine and match its data banks, link coded data and re-identify health information?
6. If the government has the right to mine, match, re-identify and contact citizens, from where is this right derived?
7. Does the MOH, its employees or contracted researchers have the right to contact potential research participants?
8. If the government’s researchers do not have the right to mine, match, re-identify and contact citizens, are there other mechanisms available that would facilitate recruitment?
9. What could the physician have done to prevent the angry phone call from his patient who believed that he had breached his obligation to keep PHI confidential?

DISCUSSION

Sociologists have demonstrated that bureaucratic systems become “embedded” and, when this happens, bureaucratic processes are not examined, understood or known by those served. Therefore, patients may not be aware that physicians submit their PHI to insurers, e.g., the government, or understand that provincial governments retain and use their PHI. Patients may be unaware that physicians are allowed to disclose PHI to third parties without a patient’s prior express consent, i.e., this privilege may never have been disclosed to a particular patient.

Paragraph 32 of the Code of Ethics reads: “Provide information reasonable in the circumstances to patients about the reasons for the collection, use and disclosure of their personal health information.”

Principle 4 of the privacy principles states: “Physicians play an important role in educating patients about possible consensual and non-consensual uses and disclosures that may be made with their personal health information.”

The elaboration that follows that principle states: “Prior to the collection of health information, the patient should be informed through means such as websites, letters, posters, flyers or conversations that their personal health information… (b) will be used to obtain payment for the health services provided; (c) may be used for health system planning and research… and (f) where possible, personal health information may be either de-identified or anonymized for any secondary purposes.”

Submitting coded data for payment is a secondary purpose. Because insurers (provincial governments) collect PHI for payment and retain it for other purposes, they are considered third-party data stewards. Physicians should tell patients that, once PHI is disclosed to a third party, the physician is no longer able to control access or use by the third party. Although Principle 13 specifically identifies electronic records, the principle should apply to paper records as well. It states: “Patients should be informed
that the treating physician cannot control access and guarantee confidentiality for an electronic health record (EHR) system.” It is noted in the commentary section, “Where possible, personal health information contained in an EHR should be de-identified before it is used for secondary purposes, such as health-system planning.”

Data stewards have limited privileges to manipulate health information. There is controversy over whether data from different ministries’ data banks should be matched with PHI for research purposes, as matching can contravene the original purpose for which the data were collected. If the information remains de-identifiable or anonymized and only aggregates are used or reported, then data stewards may match data from different data banks.

According to Principle 11 of the privacy principles, “Physicians should be aware of applicable requirements before collecting, using or disclosing personal health information for research purposes.” In the example, the physician did not disclose PHI for research purposes; original disclosure was probably for billing purposes. However, Principle 3 of the privacy principles states: “Physicians must handle personal health information in compliance with the applicable federal and provincial privacy laws and professional regulations.” One may assume that if the government is allowed to collect, retain and match data, this would be enabled by that jurisdiction’s privacy laws.

Data stewards should understand that the greater the number of discreet pieces of information collected, matched and shared, the easier it becomes to identify data subjects.

### ANSWERS

1. **Should the MOH and, by association, its employees be considered members of the circle of care?**
   
   **No, the agency and its employees do not provide direct clinical care.**

2. **Are the data being used for health system planning or research?**
   
   **They are not being used for system planning. The data are being used for health research, but not health system research.**

3. **Is this a quality-assurance study?**
   
   **By strict definition, no, because it contains qualitative components. Data are not being used to determine whether standards of practice are followed.**

4. **Should this be considered a primary or a secondary purpose?**
   
   **A secondary purpose, as a third party is using the data for research purposes. Primary purposes assist with clinical care or provide direct benefits to the data owner.**

5. **Does the government have the right to mine and match its data banks, link coded data and re-identify health information?**
   
   **A qualified yes. Governments (insurers), as data stewards and third parties, may manipulate de-identified health information within set parameters.**

6. **If the government has the right to mine, match, re-identify and contact citizens, from where is this right derived?**
   
   **Depending on the jurisdiction, provincial legislation may grant the right to mine, match and re-identify health information. The right may extend**
to contacting citizens for other purposes, e.g., inclusion in a disease registry.

7. Does the MOH, its employees or contracted researchers have the right to contact potential research participants?

Not unless specifically granted by legislation. Insurers and researchers do not have the moral right to contact potential research subjects. The primary intent of research is to generate new knowledge, and there is no guarantee that research participants will benefit from participating. The data owner may be unaware that his/her PHI is shared with a third party. Research ethics dictates that initial contact should come from a health care provider with whom the data owner has or had a therapeutic relationship, e.g., a member of a circle of care.

8. If the government's researchers do not have the right to mine, match, re-identify and contact citizens, are there other mechanisms available that would facilitate recruitment?

Yes, public service announcements, advertisements or initial contact through a member of the original circle of care who contacts potential participants, introduces the study to them and provides the researchers' contact information or obtains permission from the potential participants to share their contact information with researchers who will then contact them.

9. What could the physician have done to prevent the angry phone call from his patient who believed he had breached his obligation to keep PHI confidential?

Disclose to new patients and to patients who reach the age of majority when physicians may disclose PHI to third parties without the patient's prior express consent. This information can be disseminated by hand-outs or posters. Patients are then aware that the physician's obligation to keep PHI private and confidential is not absolute or universally obligatory. The Privacy Wizard is available for physicians to develop tools to disclose privacy practices.