SUBMISSIONS TO: Royal Commission of Inquiry into the Confidentiality of Health Records in the Province of Ontario

FROM: Canadian Civil Liberties Association

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June 11, 1979

C O N T E N T S

INTRODUCTION

The Canadian Civil Liberties Association is a national organization with a cross-country membership of some 5,000 individuals, nine affiliated chapters, and some forty groups which in turn represent several thousands of people. A substantial proportion of these people live in the Province of Ontario. The membership is drawn from all walks of life including lawyers, professors, trade unionists, media performers, writers, etc.

Among the objectives which inspire the activities of our organization is the continuing effort to enhance and protect the dignity of the individual. It is not difficult to appreciate the relationship between this objective and the work of this Commission. In essence, confidentiality concerns dignity. The more that personal privacy can be invaded without just cause, the greater the risk that people will be reduced to what former Chief Justice McRuer called "micro-organisms of the state".

The Canadian Civil Liberties Association appreciates the efforts of this Commission to resist these dehumanizing trends in the health field. To the extent that the Commission's hearings have identified so many of the facts, the public has received an invaluable education. Together with the Commission's ultimate recommendations, the exercise here has inspired the hope that the requisite action will be taken.

A word about the ensuing submissions. They reflect the CCLA concern for this loss of privacy and the need to accord it greater protection. But while privacy is crucial, we recognize also that no value is absolute. Thus, much of what follows is an attempt to strike an ever more reasonable balance between the confidentiality of health data and the other vital interests with which it must frequently compete.

In view of the fact that the Commission was created under the authority of an Ontario statute, our brief assumes the continued application of the overriding federal law, particularly in the area of criminal law enforcement. This is not to suggest, of course, that the Canadian Civil Liberties Association is necessarily pleased with the status quo in the federal domain. It does, however, reflect our recognition that if any one presentation attempts too much, it risks achieving too little.

TOWARD GREATER PROTECTIONS FOR PATIENTS

The confidentiality of health records involves, first and foremost, the issue of human dignity. To the extent that information about us passes beyond our control, there is a potential loss to our dignity. The more intimate the information, the greater is the potential loss. In the case of health records, it is obvious that we are dealing with some of the most intimate details of our lives.

In the medical care setting, the threats to dignity are compounded by the patients' vulnerability. Their health, sometimes even their lives, may require that their doctors know almost everything there is to know about them. It is crucial, therefore, that patients feel secure about the uses of the knowledge which their doctors acquire about them. Without that feeling of security, there is too great a risk that the amount of disclosure made will be insufficient to ensure proper diagnosis, treatment, and recovery.

No doubt, such considerations lie behind the historic concern of the medical profession with the ethics of confidentiality. Unfortunately, however, professional ethics alone is not an adequate protection for the patient. It reflects no disrespect for the integrity of our doctors to recognize that they often face competing ethical demands. In fairness to them as well as the patients, society as a whole, not just a single profession, should attempt to resolve the conflicts and prescribe the standards of acceptable conduct. Moreover, doctors are not the only ones whose employment creates access to health information about patients. In addition to the obvious encounters which nurses and office receptionists have with such data, our expanding health care system provides varying degrees of access for a host of other people - hospital and government record keepers, computer analysts and programmers, OHIP payment control officials, file clerks, etc. Changing concepts of health care are also creating varying degrees of access for other professionals such as psychologists and social workers. In order for patient confidentiality to be adequately protected, it is obvious that the standards to be adopted must apply to everyone whose duty involves access to the information.

While the existing laws do attempt to deal with these problems, their provisions are too vague and narrow to afford the patient adequate protection. In some respects, the existing law applies its obligations to some health care personnel and not to

others. In some areas, the obligations must be determined by inference; they are not spelled out in explicit terms. As the evidence before this Commission has revealed, the existing statutory confusion has spawned in practice a number of departures from the ideal of patient confidentiality.

In the opinion of the Canadian Civil Liberties Association, what is needed is a clear statutory enshrinement of the principle that the effective control of patient information must reside in the patient affected. In practice, this would mean that, presumptively at least, two consequences would follow:

1. Patients would have a right of direct access to their own records.
2. Those who handle the records would have a duty to avoid disclosing their contents to anyone except the affected patients.

The statutory protections must be drafted broadly enough to include the non medical as well as the medical information which is contained in these records. So often various categories of social data are collected because of their assistance in diagnosis and treatment. If such matters were not accorded the recommended protections, there might be a concomitant and harmful temptation for patients to withhold the data from their doctors.

In order to make these protections workable, the law should provide clear avenues of enforcement and redress. As far as records access is concerned, the physical property might reside in the custodians but the patient should be entitled to look at the material and obtain a copy of it. This should be enforceable by an inexpensive and expeditious procedure through court order, if necessary. As far as unauthorized disclosure is concerned, the law should make it a prosecutable offence at the instance of the Crown and an actionable tort at the instance of the patient. Since we are recommending both avenues of redress, we would suggest that the Commission consider also the possibility of empowering the convicting court to order restitution and/or damages to the victim. In the case of a lawsuit, the burden of proving the disclosure should be on the plaintiff, but the defendant should have to prove the authorization.

While seeking to create these rights and remedies, the Canadian Civil Liberties Association recognizes also that there are no absolutes. Invariably, even these vital principles will have to yield to some exceptions. We would urge, however, that those who seek to invade the principle of patient control be required to demonstrate the primacy of the interest to be served and the necessity of the means to be used. Even at that, there ought to be additional safeguards to minimize the risk of abuse. The remainder of this brief will attempt to apply these guidelines to some of the more important exemption proposals.

RE: THE EXCEPTIONS TO PATIENT ACCESS

Some constituencies have argued that patient access could be more harmful than helpful. Examples have been cited to convey the breadth and depth of injury which such an enactment could create for patients. There was even a suggestion that patient access could endanger other people. One spokesman, for example, apparently would deny such a right to the criminally insane on the grounds that its exercise could identify and, therefore, imperil those who may have informed against them.

With respect, these are not reasons to deny general patient access. At most, they are reasons for selected exceptions to such access.

As far as injury to the patients themselves is concerned, there may be an arguable basis for a legislated exception to the extent that the Commission can discern and articulate, with precision, a category of overriding health interests which access would seriously harm. As far as the protection of other people is concerned, a statutory exception might be provided to the extent that there are reasonable grounds to believe such access is accompanied by a significant risk of serious injury. But, as indicated, these should be seen only as exceptions to, not as arguments against, a right of patient access. Moreover, even in those cases where a claim for exemption is made, the matter should be subject to the adjudication of a court or other independent tribunal rather than the unilateral determination of the records custodian. And, even if direct access is denied, this should not apply to the patient's legal counsel or accredited representative where their access is deemed necessary to protect the patient's rights.

In recommending the establishment of these access rights, we do not seek to intrude upon the practice of some health care workers to write and keep confidential their own memoranda apart from the official patient records. But, in order to prevent the preservation of this practice from becoming a camouflaged exception to what we are recommending here, the resulting statute should specify more precisely what categories of information must be recorded for patient access. It should also specify that such items may be increased, but not reduced, by regulation. In any event, whatever separate notes the health care worker may be entitled to keep, they would remain subject nevertheless to rights of subpoena and powers of warrant. In most other respects, such notes should be rendered generally non-discloseable, without patient consent. Moreover, no patients should be subject to adverse adjudication which is based upon material to which neither they nor their representatives have had prior access.

RE: THE EXCEPTIONS TO NON-DISCLOSURE

As indicated, the law should contain, presumptively at least, an explicit prohibition against disseminating the contents of health records. This section discusses some of the proposed and permissible exceptions. In general, there are three acceptable avenues through which such exceptions might be exercised:

1. patient consent
2. court order
3. explicit statutory authorization.

It is obvious that disclosures would be permissible on the consent of the affected patient. To the extent that patients are in effective control over the dissemination, our underlying principles are satisfied. Yet this phenomenon is not devoid of difficulty. Suppose the circumstances are such that there is some doubt whether the patient's consent represented a voluntary and informed decision? In a later section, our brief makes a number of proposals for dealing with this problem.

As far as court orders are concerned, it has the virtue of providing at least for an independent assessment of the competing interests involved. Where a warrant or subpoena has been issued, there is usually less anxiety about the exercise of self-serving and arbitrary authority. Perhaps, however, there are certain categories of health information which in some situations should be immune even to a judicially authorized invasion? A later section responds briefly to this possibility within the limits of the provincial jurisdiction.

At times, however, there will be exceptions which by their nature are not amenable to court order and will not receive patient consent. Some will be compulsory; some may be permissible. But, in order to accord the principle of confidentiality the protection it deserves, such exceptions should require explicit statutory authorization. In other words, the safeguard of a legislative debate. In the several sections which follow, we deal with a number of the existing and proposed statutory exceptions which fall into this category.

A. DISCLOSURE WITHOUT COURT ORDER OR PATIENT CONSENT

(1) For the Enhancement of Individual and Public Health

Inevitably, when patients submit themselves to the care of particular doctors, they must expect that they will be the subject of certain communications between those doctors and other personnel involved in the health care system - nurses, receptionists, orderlies, other doctors, etc. So long as the communication is necessary to the diagnosis, treatment, care, and recovery of that for which the patient sought medical assistance, we would find it difficult to object. To whatever extent, however, communications about the patient exceeded what might be called the patient's reasonable expectations, the law should require a specific consent. Thus, an unexpected multi-disciplinary conference concerning a problem of which the patient is unaware or a disclosure to a research worker - both of which identify the patient - should be unlawful without the patient's specific consent.

The St. Thomas-Elgin General Hospital raised before this Commission the issue of what access, if any, hospital boards should have to the health records of their patients. Some of the members of the board sought a report on each abortion application which would have revealed, among other things, date of last live birth, number of children, name of physician, and age of mother. Even though the patient, herself, would not have been named, the information requested might well have enabled the recipient to identify her in a community the size of St. Thomas. Unfortunately, the current law does not adequately clarify how much of such information may or must be available to hospital boards. In our view, the law should ensure a sufficient flow of information to enable these boards and, indeed the entire public, to know and understand by what policies the medical decisions are being governed. For the board, this would be necessary to the performance of its administrative, managerial, and policy making functions. For the public, this would be necessary to the exercise of its ultimate right of scrutiny and review.

In our view, however, those members of the St. Thomas-Elgin General Hospital Board were seeking a level of information far beyond what was necessary to the performance of their legitimate oversight function. In order to discern and review the policies of the therapeutic abortion committee, it was not necessary to inspect every abortion application form. It would have sufficed to have aggregated and statistical data where the applicants could not be so readily identified. Indeed, they might have been given most of the data they were seeking so long as it was aggregated and not individualized. In order to clarify and more appropriately resolve the balance between the interests of public access and personal privacy in the government of public hospitals, the Commission should recommend statutory amendments along these lines.

The law currently requires medical practitioners to report the existence of certain communicable diseases such as syphillis. To the extent that the diseases or impairments involved are physiologically discernible and seriously dangerous to the lives, limbs, and health of other people, there would be an arguable basis for permitting an exception to the rule against disclosure. Since we cannot now respond to every relevant enactment, it will suffice for present purposes to suggest that existing and future legislative proposals be required to meet at least the above test. Moreover, whatever legislation on this subject is retained or enacted, the compulsorily reportable diseases should be identified in specific terms. This would reduce the risk of needless breaches of patient trust and provide the public with the safeguard of a legislative debate before it sustained any additional invasions of confidentiality.

(2) For State Security

There was some indication in the testimony before the Commission that the RCMP periodically seeks access to medical records in order to perform a security check on persons wishing access to classified government information. While the protection of state security must rank high among the values we revere, this proposed exemption appears to be devoid of merit. If health information is deemed necessary to establish the absence of security risks, the affected parties can always be asked

to grant consent for the inspection of their records. If they refuse, of course, they might legitimately be denied their security clearance. Thus, there appears to be no basis for a compulsory and surreptitious inspection of their records.

Further evidence before the Commission indicates that in at least one case the RCMP used secretly obtained information in order to foment dissension within the ranks of a Trotskyist organization. Apparently, the RCMP circulated, among the members of this group, some psychiatric data about one of the officers. The material was supposed to discredit him.

It is difficult to conceive of a justification for such encroachments by agents of the government, particularly in the arena of domestic activity. In any event, the federal authorities can always provide for a warrant-granting mechanism if they deem the security threats great enough. But the provincial authorities have no business providing non-warrant access for such questionable purposes.

(3) For Law Enforcement

The Commission has received a number of exemption proposals which are designed to assist the vital interests of law and order. Some police authorities would like access to confidential health information in order to deal with highjackings, rescue hostages, locate suspects, apprehend dangerous people, investigate gunshot and stab wounds, etc.

In view of the high priority we attach to the interests of confidentiality, we cannot justify an encroachment merely because it would help the activities of law enforcement. That would constitute too wide a loop-hole. Since it would not be subject to the kind of impartial scrutiny which is supposed to be involved in judicial search warrants, it could precipitate widespread and needless prying into medical data. The police would be increasingly tempted to use the most convenient sources of investigative information. The effective protection of confidentiality cannot coexist with an open-ended discretion to pry.

At the same time, however, this does not rule out a possible justification for some such disclosures to the police. In view of the compelling public interest in curtailing physical violence, there might be an arguable basis to permit a narrowly and precisely drawn exception for such purposes. Subject to the adoption of effective safeguards to minimize the risk of abuse, health care workers might be relieved of the obligation to conceal information in those situations where they reasonably believe there is a significant risk of serious bodily injury. In other words, where such circumstances apply, health care workers might be allowed, but not compelled, to disclose sufficient data to avert the anticipated harm. Thus, even in the absence of a warrant, a psychiatrist might be able to use whatever he or she knows about a patient to assist the police in the event that such patient were involved in a highjacking or hostage taking incident. Conceivably, psychiatrists could even alert the police in advance of whatever such plots their patients may have confided to them.

Despite the high priority we attach to the curtailment of violence, we nevertheless oppose any compulsion of oral reporting or assisting in these situations. Since most citizens are not compelled to provide such assistance or disclosure, it would be improper to impose this way on the sanctity of the doctor-patient relationship. In the absence of a court order, why should health care workers, of all people, incur an obligation to breach these confidences?

In such highly volatile situations, our resistance to compulsory disclosure may seem peculiar in the light of the existing legal requirement to report communicable diseases such as syphillis. But, while a breach of confidentiality can create problems for a physical patient, it can be devastating to the psychiatric patient. Moreover, in the physical cases, there are relatively objective standards by which the duty of disclosure may be discerned. In the psychiatric situations, however, the component of subjective and unreliable judgment is so much greater. The anticipation of serious injury does not arise only, of course, in the kind of clear-cut situations mentioned above. Indeed, the psychiatric literature is full of material indicating that profession's predisposition to over-predict dangerousness. The unreliability of such judgments would be compounded by making the health care

workers liable for a failure to disclose. In order to protect themselves, they would be tempted to err on the side of reporting too much. For the sake of what may be questionable benefits, it is doubtful whether the state should compel such invasions of personal privacy and obstructions to effective therapy.

While bullet and knife wounds are more objectively discernible, they too should not be subject to a requirement of disclosure. Unlike syphillis, a bullet or knife wound does not necessarily reveal a significant risk of further injury. They can and often do signify nothing more than an isolated, innocent accident. In such situations, therefore, it would be improper to compel a breach of confidentiality. Nor should it be permissible for the health care worker to disclose such data, unless the particluar circumstances suggested a continuing risk of serious injury.

But even with any permissible exceptions for serious injury, it would be necessary for the Commission to address the inevitable concerns about possible abuse. Such concerns would arise most often in those cases where the initiative for the disclosure comes not from medical personnel, but from others such as the police seeking data from them. Among the more obvious safeguards which these situations would require, for example, is a prohibition against disclosing the kinds of information which are amenable to a search warrant. Since it is better for these matters to be determined according to due process of law, that should be the mandatory route whenever it is applicable. Either before or after the data is released, the recipient might also be required to swear a special affidavit setting out the material facts and allegations involved; copies of the affidavit might be filed with the health professional concerned, the Crown Attorney, and perhaps even the College of Physicians and Surgeons. In any event, the authority to make these non-compellable disclosures should be limited to specified categories of accredited professionals. As a further measure, the Commission should consider a statistical reporting requirement similar to what the law now provides for electronic surveillance. Some element of public scrutiny might reduce, at least somewhat, any residual propensity to encroach improperly.

In the absence of such apprehended risk of injury, how far, if at all, may health care workers inform the police of the past, present, or future attendance of some wanted person at their treatment facility? To the extent that the health care workers can identify the wanted person from an external description, there is no reason to distinguish their rights and obligations in this situation from those which would apply to all other citizens. In other words, they may, not must, cooperate with the police. If a merchant or barber can notify the police about a certain redhead on the premises, why can't a doctor or a nurse do so?

The situation would be different, however, where the identification depends upon a more intimate or intrusive medical examination. It's one thing to identify someone by reference to red hair; it's another thing entirely to make the identification by reference to a hiatus hernia, coronary thrombosis, or bowel obstruction. For health care workers to disclose that any person under their treatment suffers from any or all of the latter three disorders is to allow generally unknown facts about that person to pass out of his control. That is the very indignity which the principle of confidentiality was designed to prevent. As indicated earlier, the fact that certain data might help the police cannot, by itself, justify such an invasion of confidentiality. For that, a more vital interest would have to be at risk.

Moreover, in the case of some specialized health facility, it might not be appropriate even to disclose the attendance of the redhead. Suppose, for example, that person were at the office of a psychiatrist? The disclosure of that fact alone would raise a strong, though not conclusive, inference that the redhead was in need of psychiatric help. Disclosures of mere attendance should be prohibited, therefore, to the extent that they are likely to reveal health data as well.

There have been references here to police efforts to use medical records for locating fugitive suspects and other missing persons. For these purposes, the police would seek to obtain non-medical data such as residence address and location of employer. Presumptively, however, we believe that people should have a right to

be left alone - to live if they please in anonymity. Since any need they may have for the medical treatment funded by OHIP might require them to furnish their address and employer, it would be presumptively improper to use such data in deprivation of their desire for anonymity. At most, there might be an argument for a warrant-granting mechanism in these situations. But we find it difficult to appreciate what interests would justify such unilateral invasions of patient privacy.

(4) For the Avoidance of Wrongful Imprisonment

Although we are unaware of this matter being raised at the Commission hearings, certain recent controversies prompt us to raise it. In view of the high priority which democracies like ours attach to safeguarding innocent people from punishment, we believe that this raises another area where health care workers may be allowed, but not compelled, to violate patient confidentiality. In the event that a patient disclosure indicates his or her apparent guilt of a criminal offence for which someone else has been charged, the health care worker should be free to report it. For such purposes, of course, the health records would be amenable to a search warrant and the health care worker would be compellable by subpoena. But such machinery could hardly be brought into play in a situation where there is no reason to suspect that the patient had made such a disclosure. In such circumstances, therefore, we would be prepared to permit a voluntary breach of confidentiality by the health care worker. In such a contest between informational privacy and physical liberty, the latter could ethically prevail.

Again, in the absence of warrant or subpoena, we would oppose a statutory compulsion on the health care worker to breach such a patient confidence. Since the law does not generally impose such obligations on other citizens, it would be improper to do so in the case of someone who is supposed to have a patient's trust.

(5) For Administrative or Family Convenience

The spouses and unemployed offspring (under 21) of OHIP subscribers are not entitled to separate coverage in that plan. They use the subscriber's number and the subscriber, therefore, may receive any correspondence involving their relations with OHIP. Thus, the spouses and children in these situations would lose the effective control over their own medical information. Even if they preferred to withhold such data from the other members of their respective households, they may effectively be unable to do so. While some medical services such as abortions are never the subject of OHIP verification letters and while physicians may provide that other kinds of services not be included in such letters, this does not appear to provide sufficient protection for the affected patient. On the basis of some of the testimony at the Commission, we learned that physicians do not often make requests against the sending of verification letters and, according to at least one witness, the option of doing so is not publicized among physicians. Perhaps even more serious is the fact that so many doctors are choosing now to bill their patients directly. The statement accompanying the refund cheque from OHIP is sent to the subscriber and shows the name of the doctor and some initials of the patient. This, in itself, makes the affected patients vulnerable to an interrogation they might prefer to avoid. The only way they can avoid all of this is to pay the bill themselves and never claim the refund from OHIP. This puts them in the invidious position of surrendering either their claims to medicare or their rights to privacy.

In our view, neither the interests of administrative convenience nor any concepts of family morality can justify such intrusions on personal privacy. Whatever the relationships within a family may be, the role of the state is to safeguard privacy. To the extent that a person can legally consent to medical treatment, there should be a concomitant right of medical privacy. This is not to say, of course, that the members of a family could not choose to share their coverage. But it is to say that they should have a right to choose otherwise.

B DISCLOSURE ON COURT ORDER

While judicially authorized invasions of confidentiality possess the virtue of subjecting the competing interests to an independent assessment, we believe nevertheless that the law is defective even in this area. Despite our limited experience in civil litigation, we are impelled to recommend the reform of at least one category of judicial power. We believe that, within the context of civil litigation, psychiatrists should not be compellable witnesses against their patients. The relationship between psychiatrist and patient, in some ways, is the most comprehensive of all medical relationships. In order for the therapy to be even minimally effective, it will frequently require the most complete trust and total disclosure. Whatever view one might take about the compulsory release of physiological data, one must appreciate how much more intrusive psychological encroachments are likely to be. It is difficult to imagine how a civil dispute could generate a value or principle which ought to enjoy a higher priority than psychiatric confidentiality. In the course of civil law suits, therefore, such relationships should be rendered at least presumptively immune to intrusion.

C. DISCLOSURE ON PATIENT CONSENT

To whatever extent patients consent, their health records would be lawfully subject to disclosure. The exercise, however, is not devoid of difficulty. In many situations, those who have an interest in perusing other people's health records will have sufficient bargaining power to extract from them a consent for excessive disclosure.

The employer-employee relationship provides one example of this phenomenon. Many employers, particularly in non-union settings, would have sufficient leverage to obtain virtually whatever kinds of consent they might wish. An over broad example surfaced during the Commission hearings. One company was requiring its employees simply to authorize the release of "medical information" to the "company".

While we recognize that employers will frequently have a legitimate interest in health information relating to their existing or prospective employees, there is no need for such blanket consent authorizations. The consent should be limited to what is necessary to fulfill the company's legitimate needs. Where conclusions rather than raw data would suffice, nothing more should be authorized. In most cases, all that the company needs to know is how fit and able the applicant or employee is to work at the various jobs available. While the medical practitioner who examined the patient, of course, would have the data upon which such conclusions are based, there is rarely a need for further dissemination to other company officials. The conclusions as to the person's fitness and ability will usually be enough.

School boards also have a valid interest in knowing about their pupils' health problems. The boards need sufficient information to protect the school community against communicable diseases and to ensure that affected pupils are not subject to activities or denied opportunities at variance with their fitness and needs.

Again, this does not mean that the school boards should be entitled to a carte blanche right of access and dissemination. In most cases, all that needs to be disseminated are the conclusions, not the raw data. Moreover, why should there be any dissemination beyond what is needed to fulfill the boards' legitimate functions?

A disquieting example of what appears to be a needlessly broad consent is the one used by the Toronto Board of Education. It asks parents to authorize a sharing of information about their children between the staffs of the Health Department and Board of Education throughout the youngsters' school attendance in the jurisdiction. On the basis of this consent, a virtually limitless number of people are granted access to unspecified categories of information for reasons and purposes which are also unspecified. But in the school setting, the relationship is similar to what obtains in the employment setting. Like the employee who wants the job, the parents want their children to be educated. So often, therefore, they will simply submit to what is asked.

At least in those situations where access to the necessities of life (job, education, insurance, etc.) is being made contingent upon a consent for other people's access to one's health records, the Commission should attempt to provide some relief against needlessly broad authorizations. As one possible measure the Commission might publicly designate those consent authorizations it has perused which in its view grant needlessly wide access. Where appropriate, such as with the Toronto School Board, the Commission might recommend administrative or legislative remedies for those specific cases.

In those situations where such necessities of life are concerned, the law might be amended to provide that wherever a consent is required, the purposes and intended uses of it must be set out in the document at issue. Sufficient particularity should be required to enable the person signing to know what information is required, who will have access to it, what interests it is designed to serve, and how it will do so. At the very least, such a measure would help to arouse public opinion in those situations where the declared purposes offend public standards of reasonableness. Especially where such public institutions as school boards are concerned, there might be some consequent political pressures to change the document. In other situations, such declarations might lead to union or consumer pressures. In any

event, this amendment could give rise to the creation of a legal remedy. On the basis of an inexpensive and expeditious procedure, the courts should be empowered to declare null and void those statements of purpose which exceed the needs for the consent and those consents which exceed the stated purposes. And, to whatever extent a particular disclosure violated the consent, this could give rise to the prosecutorial and tortious remedies recommended earlier.

Throughout the law with respect to the granting of such consent, there should be a requirement that each recipient of a disclosure should be bound, in turn, by the limits of the original consent.

D. ADDITIONAL SAFEGUARDS AGAINST EXCESSIVE DISCLOSURE

In order to promote the fullest possible coexistence between the protection and exceptions for confidentiality, it will be necessary for the law very clearly to prohibit the acquisition of health information by false pretenses. Whether lies are told to induce consent, obtain a subpoena, or persuade a health care worker to talk, the conduct should amount to a legally punishable offence. In the absence of such an enactment, there may be too great a temptation to distort.

But even if a piece of health information were properly released in the first instance, its subsequent transmission might be questionable. As an added protection, therefore, the law should clarify the position of those whose duty involves access to health data according to the foregoing exceptions. Such people should generally be bound by the terms and purposes for which they received the data in question.

Sometimes even if it is necessary to disclose health data without the requisite consent, it is possible nevertheless to accord some protection to the patient's proprietary interests. At least in those situations where the disclosure has occurred by the compulsion of law (certain diseases, warrant, subpoena, etc.), there should be a presumptive requirement that the patient be told. Moreover, another safeguard might be adopted for both these situations and those voluntary disclosures which respond to the risk of serious bodily harm. As suggested earlier, the Government should be required to publish, in statistical form, the experience with such health data. This will enable a continuing public evaluation of the costs and benefits of these exemption categories. Just as eternal vigilance is the price of liberty, so is adequate knowledge the pre-requisite of vigilance.

SUMMARY

The following represents a summary of the recommendations and observations contained in this brief.

TOWARD GREATER PROTECTIONS FOR PATIENTS

1. In order to ensure greater patient protection with respect to health information, presumptively at least, the following measures should be adopted:
    a) patients should have a right of direct access to their own health records
    b) those who handle such records should have a duty to avoid disclosing their contents to anyone except the affected patient.

2. Patient access should be enforceable by court order which can be obtained inexpensively and expeditiously.

3. The prohibition against improper disclosure should be enforceable by prosecution and a civil cause of action.

RE: THE EXCEPTIONS TO PATIENT ACCESS

4. While there might be exceptions to protect the patient and others from certain serious harms, such claims should be subject to independent adjudication.

5. In any event, the patient's legal counsel or accredited representative should be able to obtain access where it is necessary for the protection of the patient's rights.

6. The law should specify what categories of information must be recorded for patient access and such items should be subject to expansion, but not reduction, by regulation.

7. In any event, no patients should be subject to adverse adjudication which is based upon material to which neither they nor their representatives have had prior access.

RE: THE EXCEPTIONS TO NON-DISCLOSURE

A. Disclosure Without Court Order or Patient Consent

8. In the absence of a court order or patient consent, the categories of permissible disclosure should require statutory authorization.

9. To the extent that they come within the reasonable expectations of the patients concerned, disclosures might be permissible where they are necessary to the diagnosis, treatment, and recovery of that for which such patients sought medical assistance.

10. To the extent that information is aggregated so as to conceal the identity of the individual patients, there could be a sufficient flow of information to enable hospital boards and the public to exercise their respective administrative, managerial, policy-making, and review functions.

11. Disclosure might be permitted (or required) to the extent that certain diseases or impairments are physiologically discernible and seriously dangerous to the lives, limbs, and health of other people. Such disorders should be identified precisely in the statute concerned.

12. No case has been made for a provincially authorized exception to serve the interests of state security.

13. Beyond the foregoing, disclosure might be allowed, but not compelled, to the extent that it is reasonably necessary to avert a significant risk of serious bodily injury; by itself, a bullet or knife wound would not fall into this category.

14. To the extent that the initiatives for such disclosure emanate from third parties (e.g. the police) the following safeguards should apply:

    a) information should not be disclosed if it is of a kind that is amenable to a search warrant

    b) either before or after the data is released, the recipient should be required to swear a special affidavit setting out the material facts and allegations involved; copies of the affidavit should be filed with the health professional concerned, the Crown Attorney, and perhaps even the College of Physicians and Surgeons.

b) a provision for an inexpensive and expeditious procedure by which the courts be empowered to declare null and void those statements of purpose which exceed the functional needs for consent and those consents which exceed the stated purposes.

D. Additional Safeguards Against Excessive Disclosure

22. The law should be amended so as clearly to prohibit the acquisition of health information by false pretenses.

23. Those whose duty involves access to health data according to the foregoing exceptions should generally be bound by the terms and purposes of such access.

24. At least in those situations where a disclosure has occurred by the compulsion of law, there should be a presumptive requirement that the patient be told.

25. For both these situations and those voluntary disclosures which respond to the risk of serious bodily harm, the government should be required to publish, in statistical form, the experience with such health data.

15. In any event, the authority to make these non-compellable disclosures should be limited to specified categories of accredited professionals.

16. Beyond the foregoing, medical personnel might be permitted to advise the police of past, present, and future attendance of some missing or wanted person at their treatment facility under the following conditions:

    a) the identification is based upon external observation, not medical examination.

    b) the treatment facility is not so specialized that mere attendance there would be likely to disclose medical information.

17. Non-medical enrolment information such as address and employer should not be discloseable from OHIP records in the absence of some special warrant granting machinery.

18. Disclosures might be permitted where they are necessary to avoid wrongful imprisonment.

19. To the extent that a person is legally competent to grant consent for medical treatment, there should be a right to separate OHIP coverage so that government agencies are not involved in making unwanted disclosures to family members.

B. Disclosure on Court Order

20. The rules of civil litigation should be amended to provide that, presumptively at least, psychiatrists would not be compellable witnesses against their patients.

C. Disclosure on Patient Consent

21. At least in those situations where the necessities of life are concerned, the law should be amended to provide the following relief against over broad consent:

    a) a requirement that the document at issue contain the purposes and intended uses of the health information; there should be sufficient particularity to enable the person signing to know what information is required, who will have access to it, what interests it is designed to serve, and how it will do so.