Information and Privacy
Commissioner/Ontario
Commissaire à l'information
et à la protection de la vie privée/Ontario

ORDER PO-2100

Appeal PA-010197-1

Ministry of Health and Long-Term Care

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BACKGROUND:

In 1996, the appellant, a medical researcher, sought access, under the *Freedom of Information and Protection of Privacy Act* (the *Act*), to drug prescription data from the Ontario Drug Benefit (ODB) database, for the purpose of a drug utilization study. The ODB database is maintained by the Drug Programs Branch of the Ministry of Health and Long-Term Care (the Ministry). The appellant sought to link health card numbers of a certain group of patients to the ODB data. In early 1997, the Ministry decided to grant the appellant's request, and the Ministry and the appellant signed an agreement dated January 20, 1997 relating to the security and confidentiality of personal information (the agreement), as required by section 21(1)(e) of the *Act* and section 10 of Ontario Regulation 460 (the regulation) under the *Act*. (The signed agreement was provided to the appellant in March 1997). According to paragraph 1 of the agreement, the appellant was to use the data only for the following purpose:

> The data will be used in a pilot study to determine the drug utilization patterns of Mt. Sinai Hospital family medicine patients in order to investigate total drug burden, potential drug interactions and drug adverse effects, disease and utilization, and associations between drug prescribing and hospitalization.

The agreement also stated the following (at paragraphs 1 and 5):

> This agreement is for a one-time feed only. A new agreement will be required for subsequent or future linkages. Upon receipt of the linkage, data analysis should be completed within a 6 month period.
>
> . . . . .
>
> The [appellant] will destroy all individual identifiers in the information by December 31, 1999. The data will be destroyed earlier if the research protocol permits.

At the time the Ministry communicated its decision to grant access, the Ministry advised the appellant that "arrangements to gain access to the requested information should be made through the [Ministry's] Drug Program Branch. Please contact [named Ministry employee] at [specified telephone number]."

The appellant states that he did in fact contact the named Ministry employee for the purpose of obtaining the ODB data, and sent him a list of health card numbers, on diskette. The appellant states that "work on data retrieval was subsequently begun by [two named Ministry employees] of the Ministry's Kingston office." However, the appellant never received any of the requested data from the Ministry. The appellant states that as a result of the unavailability of the data, he lost the financial support of a private sector sponsor for the drug utilization study.

In 1999, the appellant received funding from Health Canada, a department of the federal government, for a proposed research project entitled "A Cohort Study of Air Quality and Utilization of Hospital Services" (the air pollution study). The purpose of the study was "to examine the effect of air pollution on respiratory and cardiac health." Subsequently, the

appellant received approval for this study from the University of Toronto and McMaster University.

In 1999, for the purpose of the air pollution study, the appellant sought access to the Ontario Hospital Insurance Plan (OHIP) and Canadian Institute for Health Information (CIHI) databases (both administered by the Ministry's Health Planning Branch). The appellant specifically sought claims and hospital discharge data from these sources. The Ministry decided to grant the appellant's request for access to the OHIP and CIHI databases, and the Ministry and the appellant signed an agreement relating to the security and confidentiality of personal information for this purpose. In 2000, the Ministry disclosed the OHIP and CIHI information to the appellant.

In May 2000, the appellant wrote to the Ministry's Drug Programs Branch, indicating that he "once again had funding to support the [ODB] linkage, and wished once again to initiate the process" of access to the [ODB database]. The appellant states he did not receive a response from the Ministry despite repeated communications, and in August 2000 he wrote to the Minister complaining about the lack of response from the Ministry.

Later in August 2000, the appellant wrote to the Ministry's Drug Programs Branch again seeking access to the ODB database for the purpose of the air pollution study and for another proposed study "for which funding applications are being submitted to the Heart and Stroke Foundation and to the Canadian Institutes of Health Research." The latter study concerned "prevention of stroke by management of risk factors such as high blood pressure, diabetes, and heart rhythm problems" (the stroke prevention study). The appellant enclosed with this letter a draft "Research and Confidentiality Agreement" between him and the Ministry regarding disclosure of ODB data for the air pollution and stroke prevention studies. Neither the appellant nor the Ministry ever signed this draft agreement.

On December 8, 2000, the Ministry's Drug Programs Branch wrote to the appellant as follows:

> This is in regards to your request for the provision of [ODB] data for research purposes.
>
> As you are aware, the documentation pertaining to your request was forwarded to [the Ministry's] Legal Services [Branch] for review to ensure there are no confidentiality concerns prior to the release of data. We have been advised that a research agreement between the ministry and yourself would not be sufficient to allow for the release of ODB data for the purposes of conducting research as stated in sections 42(a) and 21(1)(e) under the [*Act*] as your request currently stands.
>
> Some of the concerns that were raised during the review include the following:
>
> - that patient consent to disclose personal information was not obtained as part of the research protocol;

- that the use of an individual's OHIP number as part of this research study does not meet the provisions stated in the [*Health Cards and Numbers Control Act, 1991*] i.e., health card numbers are intended to be used to obtain public health services and the collection of health card numbers for research purposes is not permitted unless designated in the Regulations; and

- there is a possibility that patients could be identified even if the personal identifiers are encrypted, due to matching of ODB data with other data provided by the ministry.

As a result, we are unable to release the ODB data requested for your proposal as it is presently designed . . .

The appellant responded to the Ministry's letter as follows:

. . . Since you did not provide the rationale for your denial, allow me to address the specifics of the legislation that permit the approval of my request. You state that the release of this information is not permitted as "stated in sections 42(a) and 21(1)(e) under the [*Act*]. This is not correct.

Section 21(1)(e) states that information may be released for a research purpose if,

> (i) the disclosure is consistent with the conditions or reasonable expectations of disclosure under which the personal information was provided, collected or obtained.

Section 21(1)(e) is clearly satisfied because your Ministry has published the following statement for holders of [OHIP] numbers: "A health care provider may use your Health Number only for payment or health administration purposes, planning research and/or epidemiological studies." While it is true that not all of the subjects in the study are my patients, all of the Health Insurance Numbers were provided to me by the subjects' physicians who are partners in the use of this information for research and/or epidemiological studies.

Section [21(1)(e)(i)] is thus clearly satisfied.

Section [21(1)(e)(ii)] states that the research purpose for which the disclosure is to be made cannot be reasonably accomplished unless the information is provided in individually identifiable form.

This section is clearly satisfied because the goal of the investigation is to study the medical treatment of health conditions in individuals and to study the susceptibility of individuals to the health effects of air pollution. From the data provided by your Ministry last Spring, I know which of the 108,000 subjects in

the cohort have been hospitalized for respiratory problems, heart disease or stroke. I also know from the data provided by your Ministry last Spring which of these individuals have been seen in their physicians' offices or hospital emergency departments for these conditions. I now need to know which medications they were prescribed so that I can study the effects of medical treatment on their diseases and their susceptibility to the adverse effects of air pollution. There is no substitute for identifiable data for these purposes.

Section [21(1)(e)(ii)] is thus clearly satisfied.

Section [21(1)(e)(iii)] states . . . the person who is to receive the record has agreed to comply with the conditions relating to security and confidentiality prescribed by the regulations.

This section is clearly satisfied because I signed a Research Agreement with the Ministry.

Section [21(1)(e)(iii)] is thus clearly satisfied. All of the requirements of Section [21(1)(e)] under the [*Act*] are thus clearly satisfied and there is no justification for denying my application under [the *Act*].

In your first bullet point you raise the concern that "patient consent to disclose personal information was not obtained as part of the research protocol." Patient consent is always a concern, but as you know this is not a requirement under section [21(1)(e)] of [the *Act*]. The rationale for not obtaining consent was clearly set out in the Research Protocol which stated:

> Ethics Considerations
>
> This protocol will be reviewed by University Ethics Committees. We plan to use personal identifiers to ascertain ER visits and hospitalization of clinic patients. Because our anticipated cohort size is at least 50,000 individuals, we do not plan to seek individual consent for record linkage. We believe that this is ethically justified for the following reasons. Firstly, we believe that it is within the range of societal expectations that physicians would be interested in details of the ER visits and hospitalizations of their patients. Secondly, we believe that there are two very different uses of patient information. In one case, a third party, such as an insurer, is interested in the patient as an individual, and third party use of this information could have direct impact on the social and economic life of that patient. In the other case, researchers wish to view the patient as a sample of the human species, and hope that the patient is representative of other humans with similar characteristics, such as age and susceptibility to the adverse effects of air toxics. The observational researcher hopes to generalize

> from the individual to the species, and hopes that the individual under observation could be replaceable by any other human with similar characteristics. For the research proposed here, individual identifiers are irrelevant and used only to identify which of our patients' charts should be reviewed and abstracted. Personal identifiers will be stripped from the data files after all relevant information is gathered. These identifiers will be encrypted and stored in a separate file (for later use should we have the need to go back and check the original data source).

This reasoning was accepted by the Research Ethics Boards at McMaster University and the University of Toronto, each of which issued ethics certificates for the project. This reasoning was accepted by your Deputy Minister who approved release of information from the OHIP and Hospital Discharge Files. This reasoning was accepted by the Ethics Committees of the various Hospital Corporations where my Research Nurses are currently abstracting study data from the charts of patients identified by the OHIP and Hospital Discharge linkages. These Hospital Corporations include the Toronto Hospital (Toronto General and Toronto Western Divisions), Mt Sinai Hospital, Scarborough General Hospital, Trillium Hospital Corporation (Mississauga and Queensway Divisions), Sunnybrook and Women's College Hospital, St Michael's Hospital (St Michael's and Wellesley Divisions), Oakville Trafalgar Hospital and St Joseph's Hospital in Hamilton.

Absence of patient consent to disclose information is thus clearly not justification to refuse my request for information.

Bullet point 2 stated: "the use of an individual's OHIP number as part of this research study does not meet the provisions stated in the [*Health Cards and Numbers Control Act, 1991*] i.e., health card numbers are intended to be used to obtain public health services and the collection of health card numbers for research purposes is not permitted unless designated in the Regulations".

This is clearly untrue. Use of our patients health numbers for research purposes is clearly permitted under Section 2(2)(b) of the Act. In addition your Deputy Minister has approved the use of Health Card Numbers for this project, and another Branch of your Ministry used these Health Insurance Numbers to provide me with identifiable data from the OHIP and Hospital discharge files.

The concern raised in Bullet 2 is thus clearly not justification to refuse my request for information.

Bullet point 3 is particularly bizarre, and leads me to wonder whether you read the application before overturning the Deputy's approval. You wrote "there is a possibility that patients could be identified even if the personal identifiers are encrypted, due to matching of ODB data with other data provided by the

> ministry." This is a very strange comment since I specifically requested identifiable data, and the entire purpose of the application is to link *identifiable* data with information on health outcomes received from other Ministry databases. How else can I investigate modifying effects of medications on the susceptibility of individuals during episodes of adverse air quality? As discussed above, the provision of identifiable data is clearly permitted under section [21(1)(e)] of [the *Act*].
>
> The bizarre concern raised in Bullet 3 is clearly not justification to refuse my request for information.
>
> In summary none of the reasons you have presented in your letter are justification for the withholding of information from this study.

Over the next few months, the appellant wrote to a number of officials within the Ministry and other areas of the provincial government, in an effort to obtain access to the data. In February 2001, the Ministry's Deputy Minister wrote to the appellant as follows:

> I refer to your recent communications with members of Ministry staff in connection with certain personal information on patients and their drug purchase patterns.
>
> I understand that you wish this information in order to complete a research project on drug utilization patterns of patients.
>
> It is this Ministry's practice to safeguard individual patients' personal information while balancing the purposes of the [*Act*].
>
> Over the recent years, disclosure of personal information has been coming under increasing scrutiny. It is in consideration of these concerns that my predecessors' authority and mine preclude such access in the context of your request. I regret that there may have been misunderstanding in this regard.
>
> Given the foregoing, the Ministry is prepared to consider any resubmission of your research proposal taking into account the need for the Ministry to maintain the confidentiality of individual patients' personal identifiers.
>
> Should this be unsatisfactory to you, you may regard this letter as my decision to refuse to enter your research agreement as proposed. Accordingly, should you wish, you may appeal this decision to the Information and Privacy Commissioner – Ontario . . .

On February 16, 2001, the appellant responded to the Deputy Minister's letter as follows:

> . . . I am not seeking your approval for this project. I have already received approval from the [Ministry's] FOI Co-ordinator and your predecessor. Before

> Walkerton, work was begun on this project by [named Ministry staff members] of your Kingston office. After Walkerton, the Director of your Drug Programs Branch has refused to complete the job. What I am seeking from you is an order to your staff to finish the job.
> . . . . .
> So, in summary, the facts are:
>
> 1) This project was approved by the [Ministry] FOI Co-ordinator;
> 2) Prior to Walkerton, work was begun on this project by employees of your Kingston office;
> 3) Prior to Walkerton, your Ministry provided information, similar to what I am requesting now, from the OHIP and hospital discharge databases;
> 4) After Walkerton your Ministry refuses to complete work on the project, resulting in sabotage of this federally-funded research project into the effects of air pollution on the health of Ontarians.

On May 28, 2001, the Ministry's Deputy Minister wrote to the appellant, reiterating the Ministry's concerns outlined in its December 8, 2000 letter and suggesting that the appellant contact this office to determine the avenues available to him, including a request to review the Ministry's decision.

NATURE OF THE APPEAL:

The appellant wrote to this office on May 28, 2001, advising of his inability to obtain ODB data from the Ministry and requesting that this office enforce the provisions of the *Freedom of Information and Protection of Privacy Act* (the *Act*). In his letter, the appellant contends that by not providing the data within 30 days of the research agreement or notifying of a time extension, the Ministry has acted contrary to sections 26 and 27 of the *Act*.

Mediation

A mediator was assigned to this file and attempted to resolve the issues in the appeal. During this stage, the Ministry provided the mediator and the appellant with background information, as well as its views about the issues in the appeal. This information is summarized below, under topical headings.

Patient consent

The Ministry provided the mediator with its views on this issue as follows:

- it would like the appellant to obtain the data subjects' consent to disclosure of their personal information due to the sensitivity and volume of information in the ODB database;

- a research ethics committee had expressed concern regarding the absence of patient consent in the appellant's study, although the Ministry did not provide this office with a copy of a letter it allegedly received from this committee;

- if the researcher is authorized under section 2 of the *Health Cards and Numbers Control Act, 1991* (*HCNCA*) to use an individual's OHIP number, the Ministry does not require patient consent;

- the Ministry does not require patient consent for all research agreements; "whether or not patient consent is required depends upon the nature of the research proposal and, among other criteria, the use to which patient data is proposed to be put, the identifiability of the patient, the reasonableness of patients' expectations of disclosure of their personal information for the proposed use, and the inability of the research being conducted without the patient's identifiable personal information or consent to use";

- "consideration for the requirement of patient consent is part of the research proposal evaluation process applied by the Ministry under s. 21(c) [sic] of the [*Act*]";

- "exceptions to the patient consent requirement depend upon the nature of the research proposal, and include consideration of the examples [raised by the Mediator] (e.g. number of patients, deceased patients, nature of information)";

HCNCA

The Ministry stated:

- under the *HCNCA*, the appellant is only able to use the OHIP numbers of his patients in his study; use of other patients' OHIP numbers would be permissible if the appellant involved co-investigators, confidentiality undertakings were signed and the co-investigators did not share their patients' OHIP numbers (or other personal identifiers) with each other;

Identification of patients and patient information through data linking

The Ministry advised the mediator that:

- "patient confidentiality could be compromised even if the OHIP numbers were encrypted, by other identifiers such as those set out in the definition of "personal information" in s. 2(1) of [the *Act*], including 'small cells'";

- the Ministry does not require that OHIP numbers be encrypted in all cases; "requirement by the Ministry for encrypted OHIP numbers depends upon the nature of the research proposal and the personal information sought;

- "consideration by the Ministry of a request for further research data to complement data provided under an earlier research agreement, is accommodated either by a proposal for an amendment to the earlier agreement or a new research proposal";

Research purpose

- the Ministry does not consider the research purpose statement contained in the 1997 research agreement to encompass the linking of ODB data and hospital data;

With respect to any new research agreement, the Ministry advised the appellant as follows:

> The Ministry's assessment of the protection of patients' personal information in entering research agreements under [the *Act*] depends upon the individual research proposal, e.g. nature of the data sought, intended use of the data, number of patients and their identifiability, in the application of s. 21(1)(c) [sic] of [the *Act*] and other legislation and Ministry policy which may be relevant to the particular proposal.
>
> a) Patient Consent
>
> "Sign on" by other physicians as co-investigators in a new research proposal, with respect to the data sought regarding their own/other patients would receive the same assessment and consideration as with any research proposal.
>
> b) Data Linking
>
> . . . [I]t falls to the researcher to propose to the Ministry a hospitalization data linkage protocol, as part of a new research proposal which the Ministry has repeatedly offered to consider and negotiate with the researcher for satisfactory resolution.
> . . . . .
> You noted that patient consent is one of the options the Ministry had considered for resolution. Our view is that informed patient consent is preferable in any research agreement. However, in the absence of informed patient consent, the Ministry looks to other options for the confidentiality and protection of personal information in research agreements.
>
> The issue of the *HCNCA* is one of the major concerns related to this research agreement. As we discussed in the teleconference, it is not merely section 2 of the *HCNCA* that is at issue; rather, the issues result from a reading of the *HCNCA* in its entirety, including section 3 and the regulations.
>
> We also discussed encryption which is a means that the Ministry uses in some research agreements to avoid the problems created by unauthorized use of health card numbers. Encryption is not the only means of privacy and confidentiality, but it is one of several conditions that adds to privacy protection.

> We also discussed an option of having other physicians sign the research agreement as co-investigators. This may help to resolve the issue of the health card numbers use but, in that case, we could only release the health card numbers of the patients to their treating physicians.
>
> In your most recent letter, you indicated that the appellant is willing to have co-investigators sign the research agreement, and that it may be possible that that avenue will help to resolve the appeal. You also indicated that the appellant does not need all data in the [ODB] database. We would need to know exactly what information in that database he requires in order to explore whether the data could be severed out. We have repeatedly offered to try to negotiate a new research agreement with the appellant which could resolve these issues, and remain hopeful that we can accomplish resolution through a new agreement satisfactory to all parties.

Inquiry process

Mediation was not successful in resolving the issues, so the appeal was streamed to the adjudication stage of the appeal process. I sent a Notice of Inquiry setting out the issues in the appeal initially to the Ministry, which provided representations in response. I then sent the appellant a Notice of Inquiry together with the non-confidential portions of the Ministry's representations. The appellant provided representations in response.

DISCUSSION:

HAS THE APPELLANT MADE REQUESTS UNDER THE *ACT* AND, IF SO, WHAT IS THEIR CURRENT STATUS?

In the Notice of Inquiry I sent to both parties, I asked them the following questions:

- Has the appellant made a request or requests under the *Act*?
- Has the Ministry made a decision/decisions under the *Act*?
- If so, what precisely is/are the dates, substance and current status of the requests and decisions?

The Ministry submits:

> The Appellant's requests for the data in his proposed research agreement in 1997 are atypical in nature in that:
>
> - the research agreement as originally proposed ("1997 Research Proposal"), was incomplete as not specifying the personal information sought from the Ministry;

- absence of patient consent to the specific personal information being sought;
- no evidence of compliance by the Appellant with *HCNCA* as concerns the collection and use of health numbers for purposes of s. 2(2) or (3) by a person who is not providing "provincially funded health resources" (as defined in s. 1 of *HCNCA*), or who is not prescribed under the *HCNCA* Regulations;
- no search fees had been estimated, or waived by the Ministry, or access fee paid by the Appellant.

Further, the 1997 Research Proposal did not proceed as an orthodox request under s. 24 and following of [the *Act*] in that:

- there was no formal request made for particular records;
- search of records to which the 1997 Research Proposal was made could not be undertaken for lack of specificity in the personal information being sought;
- no index of (severed) records were prepared by the Ministry.

Early decisions by the Ministry approving the 1997 Research Proposal were premised on the specificity of the records sought (prior to the proposed destruction date), and the names of the researchers.

It is assumed, though not admitted, that the 1997 Research Proposal constitutes a request for purpose of this Inquiry, subject, however, to the last paragraph under this Issue . . .

The decision by the Deputy Minister dated February 14, 2001 to decline disclosure of the data sought by the appellant referred the appellant to [the IPC] *for comment* on the Ministry's decision and invited the Appellant to resubmit a revised research proposal to the one which had been submitted in 1997 [Ministry's emphasis].

The appellant submits:

. . . [Is the Ministry] attempting to cover-up the fact that I am not appealing the management of a *proposed* research agreement? [The Ministry] approved the *proposed research agreement* and the Deputy Minister signed the *actual research agreement* in March 1997.

. . . . .

The layout of all three Research Agreements, including the two signed by the Ministry in 1997, were similar. The exact data fields to be provided by the Ministry were determined in discussions with Staff . . .

The appellant goes on to state that none of the requirements regarding patient consent and compliance with the *HCNCA* cited by the Ministry are actually required under the *Act*,

and submits that the Ministry's representations ignore the fact that the Ministry already stated in a letter to him in January 1997 that the requirements of the *Act* had been met, providing the conditions later set out in the January 1997 agreement were satisfied.

The appellant argues that the Ministry's submission with respect to access and search fees under the *Act* is irrelevant, and that in fact he did make a formal request for specific records. The appellant states:

> I submitted to staff at the Kingston office a diskette with the Health Insurance Numbers of the subjects in the study. I discussed with [named Ministry employees] of the Kingston office those data fields required for the study.

Regarding the Ministry's submission respecting the index of severed records, the appellant states "I have no idea what this means."

Finally, with respect to the Ministry's submission that "early decisions by the Ministry approving the 1997 Research Proposal were premised on the specificity of the records sought (prior to the proposed destruction date), and the names of the researchers", the appellant submits:

> This idea seems to be invented after the fact. [Named Ministry employee] clearly stated that the requirements of the [*Act*] as stated in section [21(1)(e)] were satisfied.

In my view, the appellant's original request for ODB data, initiated in 1996, and ultimately granted by the Ministry in 1997, can no longer be considered an active request under the *Act*. This request clearly was for the purpose of the drug utilization study, as set out in the 1997 agreement between the appellant and the Ministry, and the appellant did not pursue the information for this study for a long period of time. Although the appellant later sought access to the ODB database, this request clearly was for different purposes, in particular the air pollution and stroke prevention studies referred to in later correspondence from the appellant in 1999 and 2000 respectively. In addition, the appellant's August 2000 letter to the Minister implied that the drug utilization study was not proceeding, and that he sought the ODB data for the latter studies. Therefore, for the purpose of this appeal, I will not rule on whether the Ministry should grant access to the ODB database as a result of the 1996/1997 request for the drug utilization study.

However, in my view, the appellant's August 21, 2000 letter to the Ministry, enclosing a draft research and confidentiality agreement, constitutes a new and valid request under section 24(1) of the *Act* for the purposes of the latter two studies, relating to air pollution and stroke prevention.

Section 24(1) of the *Act* reads:

> A person seeking access to a record shall,
>
> (a) make a request in writing to the institution that the person believes has custody or control of the record;
>
> (b) provide sufficient detail to enable an experienced employee of the institution, upon a reasonable effort, to identify the record; and
>
> (c) at the time of making the request, pay the fee prescribed by the regulations for that purpose.

The Ministry states that the appellant's requests are "atypical". In my view, the factors cited by the Ministry in support of this submission do not render the requests invalid under the *Act*.

The Ministry's submissions on the "atypical" nature of the appellant's requests focus on the 1996/1997 drug utilization request and agreement. As I found above, this request is no longer current and as such is not before me. However, I will consider the Ministry's submissions on this point in relation to the August 2000 air pollution/stroke prevention requests.

The Ministry submits that the requests are "incomplete" and do not specify the personal information sought. The implicit suggestion is that section 24(1)(b) was not complied with. The August 2000 draft agreement the appellant sent to the Ministry sets out in Appendix A a list of 11 data fields from the ODB database that the appellant seeks (the ODB database contains more than 11 data fields). The 11 data fields the appellant listed are:

- health insurance number
- ODB eligibility number
- date of service
- drug identification number
- quantity
- days supply
- total amount
- pharmacy ID
- pharmacy postal code
- MOH prescriber ID (Scrambled - to be used to identify prescribing by multiple providers)
- prescriber specialty

In my view, the requests contain a sufficient level of specificity such that they meet the requirements of section 24(1)(b) of the *Act*.

The Ministry suggests that the "absence of patient consent" should somehow invalidate these requests. The absence of patient consent is irrelevant to this issue, although this point may well come into play in any analysis under section 21(1)(e).

The Ministry refers to the *HCNCA* and submits that there is "no evidence of compliance" by the appellant with this statute. Again, this issue is irrelevant to this consideration, although I will address the applicability of the *HCNCA* below.

The Ministry submits that "no search fees had been estimated, or waived by the Ministry, or access request fee paid by" the appellant. The Ministry has essentially denied the appellant's August 2000 request for access, so whether or not it has requested or been paid search fees are irrelevant considerations. As far as the request fee is concerned, while this is a requirement under section 24(1)(c), in the circumstances, I find that the Ministry cannot now rely on its own failure to ask the appellant for this fee as a basis for invalidating the appellant's request. However, I will include an order provision requiring the appellant to pay this fee, should he wish to proceed with his request, and this payment will cure the technical defect.

The Ministry also relies on the fact that it prepared no index of records. Again, this fact is irrelevant to the question of whether or not the appellant made a valid request for access to information in August, 2000.

In conclusion, I find that the appellant has made a valid request for information under section 24(1) of the *Act* as specified in his August 21, 2000 letter to the Ministry and attached draft research and confidentiality agreement, for the purpose of the air pollution and stroke prevention studies. Further, the Ministry has, in effect, denied access to the requested information pursuant to the section 21 exemption.

JURISDICTION OF THE COMMISSIONER TO HEAR THIS APPEAL

The Ministry submits:

> There is not [sic] entitlement under [the *Act*] for requestors to avail themselves of personal information for research purposes, other than as determined by the Ministry. Such determinations depend upon presentation to the Ministry for consideration, cogent and probative evidence by the Appellant in order for the Ministry to decide, in its discretion, whether or not to permit disclosures of personal information for research purposes under s. 21(1)(e) . . . , after balancing the competing interests of [the *Act*] set out in s.1, and, in particular, in this matter, respect for the limitations on the collection and use of health numbers under the *HCNCA*.

I disagree, and find that this office may, on appeal, determine whether or not the Ministry must grant the appellant access to the information sought. Sections 10(1) and 21(1)(e) of the *Act* read:

> 10. (1) Every person has a right of access to a record or a part of a record in the custody or under the control of an institution unless,
>
> (a) the record or the part of the record falls within one of the exemptions under sections 12 to 22; or

> (b) the head is of the opinion on reasonable grounds that the request for access is frivolous or vexatious.
>
> 21. (1) A head shall refuse to disclose personal information to any person other than the individual to whom the information relates except,
>
> (e) for a research purpose if . . .

The section 21(1)(e) exception goes on to list criteria for its application.

The provision granting a right of appeal from an access decision, section 50(1)(a), reads:

> A person who has made a request for,
>
> access to a record under subsection 24(1);
>
> . . . may appeal any decision of a head under this Act to the Commissioner.

In my view, the appellant made his request under section 24(1) pursuant to his right of access to records in the custody of the Ministry under section 10(1). The Ministry has relied on the personal information exemption at section 21 to deny access, while the appellant takes the position that the section 21(1)(e) exception to the exemption applies. The Ministry believes for various reasons that the exception does not apply. In these circumstances, on appeal under section 50(1)(a), this office may determine whether or not the exemption applies. If I find that the exemption applies, I may uphold the Ministry's decision. If, on the other hand, I find that the exemption does not apply, I may order the Ministry to disclose the information.

While, in my view, section 50(1)(a) empowers the Commissioner to entertain an appeal involving section 21(1)(e), the legislative history of the *Act* lends further support to the view that, in the circumstance of a request for personal information for a research purpose, this office may conduct an inquiry and decide whether or not to order disclosure. *Public Government for Private People: The Report of the Commission on Freedom of Information and Individual Privacy/1980* (Toronto: Queen's Printer, 1980) (the Williams Commission report), which led to the passage of the *Act*, the authors state (at pages 332-334):

> . . . We recommend that the public interest in access to government information for research purposes be expressly addressed in [the personal privacy exemption] and identified as a basis for providing access to personal information. However, the circumstances in which research access is allowed should be carefully circumscribed and appropriate terms and conditions for the use of such data should be imposed in order to ensure that confidentiality is preserved . . .
>
> . . . . .
>
> Although we are in general agreement with [proposals of the U.S. Privacy Protection Study Commission (PPSC)], we wish to ensure that statutory provisions relating to research access to identifiable personal data are in accord with the approach taken under the U.S. FOIA and, in particular, with the decision

> in *Getman v. NLRB* [450 F. 2d 670 (A.C. Cir., 1971)]. With this object in view, we would alter the PPSC proposals in two respects. First, in setting out criteria for approving access for such purposes, mention should be made of two factors considered relevant by the *Getman* court: the competence of the researchers making the request and the soundness of the research proposal. We believe that both factors are highly material and that they should be specifically mentioned in the section. *Second, it may be noted that under the PPSC proposals, the decision to grant access is ultimately left to agency discretion. In* Getman*, however, access was granted as a matter of right. We believe that the latter approach is preferable. The importance of access to government information for research purposes, attested to in* Getman *and considered at length in Professor Flaherty's Commission paper . . ., is such that access should be granted as a freedom of information right. Moreover, there is the possibility that where the ultimate effect of research may be to expose inadequacies in government programs, the officials in possession of pertinent information may find themselves in a position of conflict of interest. Further, if the access question is left simply to the discretion of the officials concerned, there may be a perception on the part of the research community, whether warranted or not, that access will be more readily given to those who are sympathetic to the aims or policies of the particular department or agency, or of the government in general. It is important, we believe, that such concerns be groundless in fact and be seen to be so* [emphasis added].

Had the Legislature intended for the decision on disclosure to be discretionary, it could have placed section 21(1)(e) in Part III of the *Act* and, in particular, section 42, which prohibits disclosure of personal information, but then indicates, in paragraphs (a) through (n) that in certain circumstances, the institution may (generally in its discretion) disclose personal information. In my view, the placement of the provision regarding disclosure of personal information for research purposes in Part II/section 21 as opposed to Part III/section 42 was deliberate, and reflects the important policy considerations discussed by the Williams Commission.

I note also that this office has, in past orders, considered whether section 21(1)(e) (or its municipal equivalent) applies in specific circumstances (see, for example, Orders M-292, M-693, M-704, P-1113 and PO-1741). In addition, on appeal, this office routinely considers the application of the other listed exceptions under section 21(1), such as paragraphs (a) and (f).

Therefore, I conclude that the Legislature intended to grant the Commissioner the power to review government decisions in response to requests by researchers, and to order disclosure where the section 21(1)(e) research exception to the exemption applies.

DOES THE RESEARCH EXCEPTION TO THE PERSONAL PRIVACY EXEMPTION APPLY?

Introduction

Section 21(1)(e) of the *Act* reads:

> A head shall refuse to disclose personal information to any person other than the individual to whom the information relates except,
>
> > (e) for a research purpose if,
> >
> > > (i) the disclosure is consistent with the conditions or reasonable expectations of disclosure under which the personal information was provided, collected or obtained,
> > >
> > > (ii) the research purpose for which the disclosure is to be made cannot be reasonably accomplished unless the information is provided in individually identifiable form, and
> > >
> > > (iii) the person who is to receive the record has agreed to comply with the conditions relating to security and confidentiality prescribed by the regulations . . .

It is not in dispute that the appellant seeks personal information from the ODB database for a research purpose. Therefore, the only remaining question is whether the three criteria in section 21(1)(e) have been satisfied here.

(i) Is the disclosure consistent with the conditions or reasonable expectations of disclosure under which the personal information was provided, collected or obtained?

The Ministry submits that the appellant:

> has not adduced any cogent or probative evidence to the Ministry that his application has satisfied the criteria set out in s. 21(1)(e)(i) and (ii), in order to assist in the Ministry's consideration and determination of whether or not the circumstances of the 1997 Research Proposal satisfy the conditions for the Ministry to permit access to, collection and use of the personal information sought by the Appellant for his research purposes.

The Ministry goes on to cite a number of authorities that relate generally to the use of personal information for research, including orders of this office and the British Columbia Information and Privacy Commissioner, but does not explain specifically how they may apply here.

The appellant submits:

> Disclosure is consistent with the conditions or reasonable expectations of disclosure because the Ministry has published the following statement for holders of OHIP numbers: *"A health care provider may use your Health Number only for payment or health administration purposes, planning research and/**or epidemiological studies.**"*
>
> . . . . .
>
> . . . [A]lthough identifiable data is received from the Ministry, the identity of individuals is not, in of itself, important. I believe that the release of identifiable data is ethically justified for the following reasons. Firstly, I believe that it is within the range of societal expectations that physicians would be interested in the causes of the Emergency Department visits and hospitalisations of their patients. Secondly, I believe that there are two very different uses of patient information. In one case, a third party, such as an insurer, is interested in the patient as an individual, and third party use of this information could have direct impact on the social and economic life of that patient. In the other case, researchers wish to view the patient as a sample of the human species, and hope that the patient is representative of other humans with similar characteristics, such as age and susceptibility to the adverse effects of air toxics. The observational researcher hopes to generalize from the individual to the species, and hopes that the individual under observation could be replaceable by any other human with similar characteristics.

The Ministry collects personal information in the ODB database pursuant to its authority under the *Ontario Drug Benefit Act* (*ODBA*). Section 13(1) of that act reads:

> The Minister may directly or indirectly collect personal information, subject to such conditions as may be prescribed, for purposes related to the administration of this Act or for such other purposes as may be prescribed.

The *ODBA* permits the Ministry to disclose ODB data, as described in sections 13(3)-(7):

> (3) The Minister shall disclose personal information if all prescribed conditions have been met and the disclosure is necessary for purposes related to the administration of this Act or for such other purposes as may be prescribed. However, the Minister shall not disclose the information if, in his or her opinion, the disclosure is not necessary for those purposes.
>
> (4) Subject to such conditions as may be prescribed, the Minister may enter into agreements to collect, use or disclose personal information for purposes related to the administration of this Act or for such other purposes as may be prescribed.
>
> (5) An agreement under subsection (4) shall provide that personal information collected or disclosed under the agreement will be used only,

(a) to verify the accuracy of information held or exchanged by a party to the agreement;

(b) to administer or enforce a law administered by a party to the agreement;

(c) for a purpose prescribed by regulation under subsection (4).

(6) An agreement under subsection (4) shall provide that personal information collected, used or disclosed under it is confidential and shall establish mechanisms for maintaining the confidentiality of the information.

(7) Before disclosing personal information obtained under the Act or under an agreement, the person who obtained it shall delete from it all names and identifying numbers, symbols or other particulars assigned to individuals unless,

(a) disclosure of the names or other identifying information is necessary for the purposes described in subsection (3) or (4); or

(b) disclosure of the names or other identifying information is otherwise authorized under the Freedom of Information and Protection of Privacy Act.

The Regulations under the *ODBA* do not prescribe any conditions or purposes for collection, use or disclosure.

A person who wishes to apply for assistance under the Ontario Drug Benefit Program fills out a Ministry form, which collects personal information including the individual's name, health number, gender, date of birth, social insurance number, telephone number and address. At the bottom of the form, the following notice appears:

The Ministry of Health and Long-Term Care collects information about prescriptions to:

- help pharmacists fill their customers' prescriptions safely and effectively;
- review trends; and
- ensure that health programs meet the needs of people in Ontario.

This information is collected with the legal authority of section 13 of the *Ontario Drug Benefit Act*, R.S.O. 1990, Chap. O.10. The information will be used to administer the Trillium Drug Program and the Ontario Drug Benefit Program. For more information, write to the Director, Drug Programs Branch, Ministry of Health and Long-Term Care, 5700 Yonge Street, 3rd Floor, Toronto ON M2M 4K5 or call 1 800 268-1154. In Toronto call (416) 314-5518.

The notice given to drug benefit program applicants does not explicitly state that personal information may be used or disclosed for the purpose of medical research. However, in my view, it is reasonable to conclude that the stated purpose of "reviewing trends" may include the analysis and linkage of the drug program data together with other data to determine the effects of certain conditions or factors on public health (such as, in this case, the effect of air pollution on health, or the determination of what factors might prevent serious illnesses such as stroke). These matters could reasonably be described as the review of trends in public health.

Secondly, in my view, it is reasonable to describe the general purpose of "ensuring that health programs meet the needs of people in Ontario" to include health studies of the nature at issue in this case. The process of ascertaining the impacts of various factors on the health of individuals is surely an integral part of ensuring that health programs meet the needs of the people of Ontario. In my view, people understand that Ontario government health programs do not exist in a vacuum, and must be continually reviewed and revised, in large part based on feedback from the scientific community, to ensure that they are most effective in meeting the health and medical needs of the public.

While it is arguable that the drug benefit program notice is too vague, to take an overly technical view of the notice to prevent disclosure would defeat the greater public interest of advancing scientific knowledge in the health care field, improving the delivery of health care programs and ultimately enhancing public health. While there is no doubt that the information at issue is sensitive in nature, I agree with the appellant that disclosure for the purpose of health research is consistent with societal expectations.

I note also that the Ministry itself apparently believes it has the authority to disclose ODB data to individuals or organizations for the purpose of legitimate medical research. For example, it is apparent that the Ministry provides ODB data to the Institute for Clinical Evaluative Studies (ICES) for its research purposes (see, for example, the current ICES project regarding "Patterns of Diabetes Care in Ontario", described on the ICES website at <http://www.ices.on.ca>).

In my view, the section 21(1)(e)(i) condition includes, by implication, a requirement that the researcher is sufficiently qualified to carry out the proposed research, and that the research proposal is soundly designed in terms of its efficacy and ability to achieve the stated objectives. The appellant clearly has significant qualifications and experience in the field of epidemiological research, and has received financial and ethical support for these specific research projects from the federal government and the research ethics committees of two universities. In addition, the Ministry has in the past recognized the appellant as a qualified researcher, and has not at any point challenged his qualifications, nor challenged the efficacy of his proposed air pollution or stroke prevention studies. In these circumstances, I see no basis for questioning the appellant's qualifications or the soundness or efficacy of his proposed research.

I find that the first condition under section 21(1)(e) is satisfied. However, conditions (ii) and (iii) under section 21(1)(e) must also apply to permit disclosure.

(ii) Could the research purpose for which the disclosure is to be made be reasonably accomplished if the information was not provided in individually identifiable form?

The Ministry makes no specific submissions on this point.

The appellant submits:

> The goal of the investigation is to study the medical treatment of health conditions in individuals and to study the relations between the prescribing of mediations and hospitalisation. From the data provided by the [Ministry's] Integrated Policy and Planning Division, I have information about which of the 108,000 subjects in the cohort have been hospitalised for respiratory problems, heart disease or stroke. Information provided by the Integrated Policy and Planning Division has also identified which of these individuals have been seen in their physicians' offices or hospital emergency departments for these conditions. With the approval of hospital Research Ethics Boards and Medical Records Departments my Research Nurses have abstracted clinical information about these patients from hospital charts. Some medication information has been abstracted from the medical charts, but these data are rarely complete. I now need to know which medications were prescribed so that I can study the effects of medical treatment on these diseases. There is no substitute for identifiable data for these purposes since the medication data must be merged with the health condition data.

The appellant has persuaded me that he requires the ODB data in individually identifiable form in order to accomplish his data linkage and analysis purposes. Based on the material before me, it does not appear that the appellant's study purposes could be accomplished were the Ministry to provide the data in non-identifiable form.

I find that the second condition under section 21(1)(e) has been met.

(iii) Has the appellant agreed to comply with the conditions relating to security and confidentiality prescribed by section 10 of Ontario Regulation 460 under the *Act*?

Section 10(1) of Ontario Regulation 460 under the *Act* reads:

> The following are the terms and conditions relating to security and confidentiality that a person is required to agree to before a head may disclose personal information to that person for a research purpose:
>
> 1. The person shall use the information only for a research purpose set out in the agreement or for which the person has written authorization from the institution.
>
> 2. The person shall name in the agreement any other persons who will be given access to personal information in a form in which the individual to whom it relates can be identified.

3. Before disclosing personal information to other persons under paragraph 2, the person shall enter into an agreement with those persons to ensure that they will not disclose it to any other person.

4. The person shall keep the information in a physically secure location to which access is given only to the person and to the persons given access under paragraph 2.

5. The person shall destroy all individual identifiers in the information by the date specified in the agreement.

6. The person shall not contact any individual to whom personal information relates, directly or indirectly, without the prior written authority of the institution.

7. The person shall ensure that no personal information will be used or disclosed in a form in which the individual to whom it relates can be identified without the written authority of the institution.

8. The person shall notify the institution in writing immediately if the person becomes aware that any of the conditions set out in this section have been breached.

Section 10(2) of the Regulation requires that a security and confidentiality agreement shall be in Form 1.

As indicated above, in August 21, 2000 the appellant sent a draft Research and Confidentiality Agreement to the Ministry, but neither party signed this agreement. The draft agreement sets out the purposes of the agreement, a number of definitions, a description of the specific personal information the Ministry would provide to the appellant, a provision regarding use of the information, accuracy, termination and other related provisions. The draft agreement also sets out a number of provisions described as pertaining to "Use" and "Confidentiality" (sections 5 and 7 respectively), as follows:

5.1 [The appellant] shall use the ODB Data provided by [the Ministry] under this Agreement, including any Derived Personal Information, only as necessary for the following research purposes:

a) to conduct research on the management of medical problems and,
b) to conduct research on the health effects of air pollution.

7.1 The ODB Data disclosed under this Agreement, including any Derived Personal Information, is confidential and mechanisms for maintaining the confidentiality of this information are described in Paragraph 7.4.

7.2 Before disclosing any ODB Data under this Agreement, the [Ministry] shall exercise due caution in providing only that information that is determined to be necessary for the purposes set out in Paragraph 5.1.

7.3 [The appellant], in requesting ODB Data obtained under this Agreement, warrants and represents that the ODB Data, including any Derived Personal Information, is necessary for the purposes set out in Paragraph 5.1.

7.4 [The appellant] agrees to the following precautions and safeguards for handling the ODB Data: including any Derived Personal Information:

(a) [The appellant] may provide access to the ODB Data to the following individuals:

None, at present.

Where an individual identified in Clause 7.4(a) no longer requires access to the ODB Data, [the appellant] shall notify the [Ministry] in writing of the name of this individual, as well as the name of any individual he wishes to substitute for those listed in Clause 7.4(a). The [Ministry] agrees to confirm the substitution by advising [the appellant] in writing within ten (10) working days of its receipt of the notification. The substituted individual(s) shall thereupon be substituted in Clause 7.4(a).

(b) [The appellant] will keep the ODB Data, including any Derived Personal Information, in a physically secure location.

(c) [The appellant] will store the ODB Data diskettes and CD-ROMs from the [Ministry] in a locked safe in a room with security locks.

(d) All personnel working with [the appellant] and using ODB data must sign a confidentiality agreement to ensure that they do not disclose ODB Data, including any Derived Personal Information, to any other person, except staff of the [Ministry] in accordance with Paragraph 14.1. In so doing, each person working with [the appellant] acknowledges that the disclosure of ODB Data, including any Derived Personal Information, is grounds for immediate dismissal or termination.

(e) [The appellant] agrees not to sell any of the ODB Data or any of the information in the data fields contained in the files provided by the [Ministry].

(f) [The appellant] agrees to destroy the ODB Data, including any Derived Personal Information, within 24 (24) months following the completion of the data analysis for the research study. [The appellant] agrees to notify the [Ministry] in writing immediately following the destruction of the ODB Data.

7.5 [The appellant] will not contact, directly or indirectly, any Recipient, Study Physician, Non-Study Physician, or Dispensing Agency or any other individual to whom the personal information relates, without the prior written authority of the [Ministry].

7.6 Subject to Paragraph 14.1, [the appellant] will ensure that no ODB Data, or Derived Personal Information will be used or disclosed in a form in which any Recipient, Study Physician, Non-Study Physician, or Dispensing Agency or any other individual to whom it relates can be identified, without the prior written authority of the [Ministry].

7.7 [The appellant] acknowledges that any person working for him who discloses the ODB Data, including any Derived Personal Information, in contravention of the confidentiality agreement the person has signed with [the appellant] will be immediately dismissed or terminated.

7.8 [The appellant] will notify the [Ministry] as soon as he has become aware of a breach of any of the terms and conditions of this Agreement.

The Ministry makes no specific submissions on this point.

The appellant submits: "Definitely. A Research Agreement containing these provisions has been signed by the Deputy Minister and by me." In addition, the appellant states:

> . . . For the research purpose here, individual identifiers are irrelevant and used only to identify which of our patients' charts should be reviewed and abstracted. Personal identifiers have been stripped from all the data files heretofore received from the Ministry after all relevant linkages have been made. These identifiers are encrypted and stored in a separate file (for later use should we have the need to go back and check the original data source.) The computer files in day to day usage contain no personal identifiers.

Section 10(1)1 of the Regulation under the *Act* is mostly satisfied by sections 5.1 and 7.2 and 7.3 of the draft agreement, with one exception. In my view, the description of the research purpose in section 5.1(a) is too vague and does not sufficiently describe the intended purpose, which I

take to be the stroke prevention study, as described above. However, the 5.1(b) description does adequately describe the purpose of the air pollution study.

Sections 7.4(a) of the draft agreement, although it does not specify an individual, adequately addresses the section 10(1)2 of the Regulation, since it appears the appellant does not intend to provide access to the ODB data to any other individuals and, if he so intends in the future, section 7.4(a) indicates that he must notify the Ministry of this fact and provide the name of the individual.

The requirement of a confidentiality agreement between the appellant and any individual given access by the appellant, in section 10(1)3 of the Regulation, is satisfied by section 7.4(d) of the draft agreement. In addition, the section 10(1)4 physical security requirement in the Regulation is adequately addressed in the draft agreement, through sections 7.4(b) and (c). The destruction requirement in section 10(1)5 of the Regulation is satisfied by section 7.4(f) of the draft agreement.

Section 10(1)6 of the Regulation deals with limits on the researcher contacting data subjects, and these limits are adequately addressed by section 7.5 of the draft agreement.

Section 10(1)7 of the Regulation limits use and disclosure of personal information. These points are sufficiently dealt with in sections 7.4(a), and (e), 7.5 and 7.6 of the draft agreement.

Finally, section 10(1)8 of the Regulation refers to the requirement of the researcher notifying the institution should the researcher become aware of any breach of the security and confidentiality provisions. These requirements are adequately addressed by section 7.8 of the draft agreement.

To conclude, I find that all of the provisions of section 10(1) of the Regulation are adequately addressed by the draft confidentiality agreement of August, 2000, with the sole exception that the research purpose in section 5.1(a) lacks sufficient detail.

In the circumstances, although this deficiency is significant, it should not be fatal to the appellant's request for personal information, since it can be remedied with relative ease. I will address this issue in the order provisions below.

In addition, although the draft agreement is not in Form 1, this is a defect merely in form and not substance, so this deficiency also is not fatal to the request.

I conclude that, subject to the curable defect relating to the description of one of the proposed research purposes, identified above, the appellant meets the third condition under section 21(1)(e).

The *Health Cards and Numbers Control Act, 1991*

As indicated above, the Ministry takes the position that the *HCNCA* prohibits the disclosure of health card numbers to the appellant. More specifically, the Ministry submits:

> The use of an individual's OHIP number as part of the research study did not meet the provisions stated in *HCNCA*, i.e., health card numbers are intended to be used to obtain public health services and the collection of health card numbers for research purposes is not permitted unless the person is so designated in the Regulations. [The appellant] stated to the Ministry that he did not enter into an agreement with any other physician which would have enabled him to collect and use health numbers as identifiers in order to release the [ODB] data.
>
> . . . . .
>
> The Appellant's requests for the data in his proposed research agreement in 1997 are atypical in nature in that:
>
> . . . . .
>
> - no evidence of compliance by the Appellant with *HCNCA* as concerns the collection and use of health numbers for purposes of s. 2(2) or (3) by a person who is not providing "provincially funded health resources" (as defined in s. 1 of *HCNCA*), or who is not prescribed under the *HCNCA* Regulations.

The appellant submits:

> . . . Section 2(2)(b) of the [*HCNCA*] explicitly states that Health Card Numbers may be used for health research or epidemiological studies. The Ministry has already used the Health Card Numbers I sent them to provide me with data in 1997 and 2000, and 2001.
>
> . . . [T]hese health card numbers were provided to me *by other physicians* for the explicit purpose of health research [appellant's emphasis].

Section 2 of the *HCNCA* reads (in part):

> (1) No person shall . . . collect or use another person's health number.
>
> (2) Despite subsection (1), a person may collect or use another person's health number for purposes related to the provision of provincially funded health resources to that other person. In addition, a person who provides a provincially funded health resource to a person who has a health card or health number,
>
> (b) may collect or use the health number for purposes related to health administration or planning or health research or epidemiological studies.
>
> (3) Despite subsection (1), a person prescribed by the regulations may collect or use health numbers for purposes related to health administration or planning or health research or epidemiological studies.

Section 1 of Ontario Regulation 147/91 under the *HCNCA* reads:

> The following persons are prescribed for the purposes of subsection 2(3) of the Act:
>
> 1. A person who manufactures health cards under a contract with the Province of Ontario.
> 2. The Canadian Institute for Health Information.
> 3. The Workers' Compensation Board.
> 4. The Institute for Clinical Evaluative Sciences.
> 5. A medical officer of health under the Health Protection and Promotion Act.
> 6. A person working on behalf of the project called HIV Ontario Observational Database.
> 7. Cancer Care Ontario.

In my view, it is arguable that the appellant does not fit within any of the exceptions to the *HCNCA* prohibition against collecting or using health numbers, since it does not appear that he provides a provincially funded health resource to the proposed data subjects, and he is not listed in the *HCNCA* regulation. However, in these circumstances, it is not necessary for me to make a specific finding on whether the disclosure would conform to the *HCNCA*.

Section 67(1) of the *Act* reads:

> This Act prevails over a confidentiality provision in any other Act unless subsection (2) or the other *Act* specifically provides otherwise.

Section 67(2) lists a number of specific statutory provisions that prevail over the *Act*. No provision of the *HCNCA* is listed here.

Even if the *HCNCA* would otherwise prohibit the appellant from collecting or using health numbers, the right of access under section 10(1) of the *Act* clearly prevails over any such prohibition. Therefore, I do not accept the Ministry's submission that the *HCNCA* is applicable to the appellant's request for health numbers (among other personal information).

However, in order to ensure that health numbers are not disclosed to the appellant unnecessarily, I recommend that the appellant provide the Ministry with both a health number and a unique research number for each data subject, and then for the Ministry to make the match using the health number, but disclose back to the appellant only the unique research number. In addition, I recommend that the appellant later destroy the health numbers he has obtained from other sources, since it appears they will no longer be necessary for these specific research projects.

Conclusion and remedy

In my view, with the exception of the defect in the description of one of the two research purposes in the draft confidentiality agreement, the appellant has established that his request meets all of the requirements in paragraphs (i), (ii) and (iii) of section 21(1)(e) of the *Act*.

With regard to the appropriate remedy in the circumstances, the appellant submits:

> The Deputy Minister of Health and I have signed 3 Research Agreements since 1996 calling for the linkage of patient Health Numbers to Administrative Data held by the Ministry. The Integrated Policy and Planning Division has provided exemplary customer service and has provided their "feeds" of data from the files of the Ontario Hospitalization database and the Ontario Health Insurance Plan. On the other hand, [named individual] failed to comply with [the *Act*] when [Ministry] staff were unable to provide me with Research Data in a timely fashion. After I wrote to the Minister of Health and the Premier of Ontario for assistance, [named individual] flatly refused to provide the data. This is clearly in violation of [the *Act*] . . .
>
> The remedy is clear.
>
> 1) The Drug Benefits Branch must be ordered to provide the Research Data in compliance with the Act.
>
> 2) I am concerned that [the Ministry will demand] an outrageous fee for the data linkage. I thus request that the [IPC] compensate me for my time wasted, and expenses incurred during the two years I have been struggling to have Ministry bureaucrats comply with the law, by ordering the Ministry to waive their fee for the data linkage. Failing that, I request that the Adjudicator place reasonable limits on the fee to be charged by the Ministry.
>
> The greatest part of the cost of performing a linkage is at the "front end" where the data provided by the Researcher must be "cleaned" and the Health Numbers validated. These tasks have already been completed by programmers at the Integrated Policy and Planning Division as the preliminary to their linkages to the Hospitalization and OHIP databases. The least costly way to proceed would be simply to have a copy of the data file transferred from the Integrated Policy and Planning Division to computer programmers in the Drug Benefits Program. I estimate that no more than 10 hours of programmers' time should then be required to link the data file to the data archives of the Drug Benefits Program. The total costs of the linkage should thus be well under $1000.

Though the Ministry did not make direct submissions regarding remedy, as noted, it submits that this office lacks jurisdiction to hear this appeal and order disclosure of the requested information. I have already considered and rejected this submission as described above.

In the circumstances, the appropriate remedy is to require the Ministry to disclose the requested data to the appellant, on the condition that the appellant does the following:

1. Amends the draft Research and Confidentiality agreement by:

   (a) including a more detailed description of the study generally described in section 5.1(a);

   (b) making any other amendments that are necessary due to the passage of time and change in circumstances, such as the relevant dates;

2. Signs the agreement and delivers it to the Ministry; and

3. Delivers a request fee to the Ministry.

The appellant is concerned that the Ministry may seek fees for access under the *Act*, and the Ministry implies in its representations that it may do so. In the circumstances, I have decided not to address this issue, unless a dispute arises over it. I remain seized of this appeal so that the appellant may contact me should such a dispute arise.

Similarly, I am not prepared at this time to make any order regarding the task of "cleaning" the health number data provided by the appellant to the Ministry. Again, the appellant may contact me should a dispute over this issue arise.

ORDER:

1. Upon the appellant's delivery to the Ministry of a Research and Confidentiality Agreement, revised in accordance with paragraph 1 under "Conclusion and remedy" above, signed by the appellant, as well as a request fee, I order the Ministry to disclose the requested information to the appellant within 30 days, or within such other reasonable time frame as may be agreed upon by the appellant and the Ministry.

2. The appellant is requested to provide this office with a copy of the materials sent to the Ministry.

3. I remain seized of this appeal so that I may deal with any matters that may arise.

Original Signed By: January 17, 2003
David Goodis
Senior Adjudicator