Information and Privacy Commissioner,
Ontario, Canada

Commissaire à l'information et à la protection de la vie privée,
Ontario, Canada

ORDER PO-4248

Appeal PA20-00051

University Health Network

March 29, 2022

Summary: This order determines the adequacy of the search conducted by the University Health Network (UHN) in response to a 14-part request for access under the *Freedom of Information and Protection of Privacy Act* (*FIPPA*) to information about the treatment of aplastic anemia at one of its hospitals. UHN conducted searches and issued a decision granting access to some responsive records while claiming that specific data in response to certain parts of the request does not exist. The appellant appealed UHN's decision to the IPC on the basis of his belief that additional records do exist. During mediation, UHN conducted a further search and located an additional responsive record to which it granted access. The appellant maintained that additional records should exist in response to three specific parts of the request, or could be produced from existing records. In this order, the adjudicator finds that UHN does not have an obligation to create a record and upholds UHN's search as reasonable.

Statutes Considered: *Freedom of Information and Protection of Privacy Act*, R.S.O. 1990, c. F.31, as amended, section 24.

OVERVIEW:

[1] University Health Network (UHN) received a 14-part request under the *Freedom of Information and Protection of Privacy Act* (*FIPPA* or the *Act*) for access to records relating to the treatment of aplastic anemia at Princess Margaret Hospital (PMH).

[2] UHN conducted a search and issued a decision granting partial access to responsive records. UHN also claimed in its decision that records containing some of the requested information do not exist.

[3] The parties continued to communicate after UHN issued its decision. Following further questions from the requester, UHN conducted another search. As a result, an additional responsive record was located, and UHN issued a supplementary decision granting full access to it.

[4] The requester, now the appellant, appealed UHN's decision to the Office of the Information and Privacy Commissioner of Ontario (the IPC), claiming that additional responsive records should exist. The parties participated in mediation to explore the possibility of resolution.

[5] During mediation, the appellant narrowed the issues on appeal to the reasonableness of UHN's search for records responsive to three parts of the request – parts 3, 7 and 8. Those three parts seek access to statistical information, and information about drug dose and treatment protocols, policies, procedures and practices relating to treatment of aplastic anemia:

> 3) I would like to know how many patients treated at Princess Margaret Hospital with an alternative treatment (not a bone marrow transplant) for Aplastic Anemia died between Jan 1st, 2014 to October 13th, 2019. More specifically how many died within the first 100 days and how many died after 100 days.
>
> …
>
> 7) I would also like to know what is considered a therapeutic range of Neoral (commonly referred to as cyclosporin) for patients post bone marrow transplant at Princess Margaret Hospital. I believe the answer to this question will be 150-400. Based upon patients who are trying to maintain a therapeutic range post bone marrow transplant (and excluding patients who are being tapered or being deliberately kept outside of a therapeutic range) between Jan 1st, 204 to October 13th, 2019 on average how often are patients found to be outside of therapeutic range when tested? In addition, in the same time frame and on average, how often are patients found to be within therapeutic range and [their] Neoral (commonly referred to as cyclosporin) dosage is changed anyway.
>
> …
>
> 8) Are patients being treated post bone marrow transplant checked more frequently for Neoral (commonly referred to as cyclosporin) if they are found to be out of range or are having dosages adjusted. If so, how often and if there is a protocol / procedure or common practice specific to this used by the bone marrow transplant team at Princess Margaret Hospital. I would like a copy of said protocol / procedure or common practice.

[6] In response to part 3 of the request, UHN wrote in its decision that 80 patients were treated with an alternative treatment, but that a record of mortality rates for

these patients does not exist.

[7] In response to parts 7 and 8, UHN granted access to a specific protocol. For part 7, UHN also wrote that no data is available about the number of patients whose levels were found to be outside of the therapeutic range for cyclosporine when tested, or of patients whose levels were found to be within the therapeutic range when tested and had their dose changed. Regarding part 8, UHN wrote in its decision that the frequency of testing depends on the time from transplant and stability of the patient's clinical situation.

[8] When no further mediation was possible, the appeal was transferred to the adjudication stage of the appeal process on the sole issue of the reasonableness of UHN's search for records responsive to parts 3, 7 and 8 of the request. I began a written inquiry during which I invited the parties to submit representations in response to a Notice of Inquiry, including reply and sur-reply representations. I also sought and received clarification from UHN regarding their reply representations (about the collection of data in response to part 3 of the request), to which I then invited the appellant to respond. The parties' representations were shared with each other in accordance with the IPC's *Practice Direction 7* on the sharing of representations.

[9] In this order, I find that UHN conducted a reasonable search for records responsive to parts 3, 7 and 8 of the request. I also find that UHN is not obligated under the *Act* to create a record in response to part 3 of the request.

DISCUSSION:

[10] When a requester claims that additional records exist beyond those found by the institution, the issue is whether the institution has conducted a reasonable search for records as required by section 24 of *FIPPA*.[1] If the IPC is satisfied that the search carried out was reasonable in the circumstances, it will uphold the institution's decision. Otherwise, it may order the institution to conduct another search for records.

[11] Although a requester will rarely be in a position to indicate precisely which records the institution has not yet identified, they must still provide a reasonable basis for concluding that such records exist.[2]

[12] The *Act* does not require the institution to prove with certainty that further records do not exist. However, the institution must provide enough evidence to show that it has made a reasonable effort to identify and locate responsive records;[3] that is, records that are "reasonably related" to the request.[4]

[13] A reasonable search is one in which an experienced employee knowledgeable in

[1] Orders P-85, P-221 and PO-1954-I.
[2] Order MO-2246.
[3] Orders P-624 and PO-2559.
[4] Order PO-2554.

the subject matter of the request makes a reasonable effort to locate records that are reasonably related to the request.[5] The IPC will order a further search if the institution does not provide enough evidence to show that it has made a reasonable effort to identify and locate all of the responsive records within its custody or control.[6]

Representations

UHN's representations

[14] UHN submits that it conducted a thorough search of its records and consulted with experts knowledgeable in the care and treatment of aplastic anemia, and that its search was reasonable.

[15] UHN submits that, before it issued its access decision, the request was sent to various staff within PMH involved in treatment of aplastic anemia. These included the senior director of pharmacy, the clinical director, the unit manager, coordinator and operations manager of the unit involved, the administrative manager of UHN's statistical unit, and individual physicians. UHN says that staff reviewed UHN's policies, procedures and guidelines, and consulted with colleagues knowledgeable in the treatment of aplastic anemia as part of efforts to locate responsive records.

[16] UHN says that the appellant sent follow-up correspondence to UHN's freedom of information and privacy coordinator (FOIC)[7] addressing those parts of the access decision the appellant felt did not answer his request. UHN submits that the appellant said he was satisfied with UHN's response to parts 1, 2, 10, 11 and 13 of the request, but not with the response to parts 3-9. For parts 12 and 14, UHN says the appellant "wanted confirmation that the response given was the 'official response' to his question."[8] UHN says it then circulated the appellant's follow-up correspondence to the same staff (noted above) for review, who located one more record that contained information responsive to parts 4, 5 and 6 of the request. UNH then disclosed this additional record to the appellant.

[17] According to UHN the result of its searches was that responsive records were located and disclosed in response to all but limited portions of the request. UHN submits that, while the records it has thus far disclosed are responsive to the appellant's request, there may simply not be recorded information that answers all of the appellant's questions. For this reason, UHN says it suggested to the appellant that he discuss his concerns about treatment directly with treating clinicians and patient relations staff.

---

[5] Orders M-909, PO-2469 and PO-2592.
[6] Order MO-2185.
[7] The FOIC is also the Manager of UHN's Privacy Operations Department, and is referred to as the FOIC throughout this decision.
[8] In his representations, summarized below, the appellant wrote that he "decided to no longer seek additional information from FOI about points 12 and 14. As I have already noted, the only issue in this appeal is the reasonableness of UHN's search for records responsive to parts 3, 7 and 8 of the request.

[18] As for part 3 of the request (for access to the number of patients that died after receiving an alternative treatment), UHN says it had previously advised the appellant that mortality rates for these patients do not exist.

[19] UHN submits that the appellant appears to want UHN to create a record by identifying and reviewing individual patient charts and then extracting the requested information (i.e. number of deaths) from them. UHN says that if the patient died in another hospital or in another jurisdiction, UHN would not have this information, and a patient's cause of death may not be linked to aplastic anemia. UHN also says that it does not have the authority under the *Personal Health Information and Privacy Act, 2004* (*PHIPA*) to access records of personal health information in order to create a record to respond to an access request under *FIPPA*.

[20] With respect to parts 7 and 8 of the request (a copy of a protocol, procedure or common practice for the drug cyclosporine governing its use for treatment of aplastic anemia, as well as specific information about the tracking of the drug's administration and dose changes), UHN says that the appellant had previously asked for statistical information in relation to cyclosporine and was told that no data exists that would respond to his specific questions about it. As mentioned above, UHN says it granted access to a protocol in response to both parts 7 and 8 and advised the appellant that, "[a]fter consulting with staff knowledgeable of the disease and its treatments," there were no additional records to disclose.

The appellant's representations

[21] The appellant submits that UHN disclosed during mediation that 80 patients "received alternative treatment / not a bone marrow transplant." In his representations, the appellant says that the specific alternative treatment to which he refers is the administration of Anti-Thymocyte Globulin (ATG).[9]

[22] He says that he wants to know how many of those 80 patients are now deceased.[10]

[23] The appellant submits that UHN should have records that show (i) the number of people who died between January 1, 2014 and October 13, 2019[11] who received ATG; and (ii) the number of people for whom UHN has "no additional records" but who received ATG to treat aplastic anemia during the same period.

[24] The appellant says that UHN seems to be "extrapolating an opinion of what information I am seeking and its interpretation" by claiming that the information is only available by accessing individual patient files, when he says that he simply seeks access to "mortality information." He questions why UHN was able to provide the requested statistics for bone marrow transplant recipients (in response to part 2 of his request)

---

[9] For the remainder of this order, I will use ATG to refer to the appellant's submissions about an "alternative treatment / not a bone marrow transplant."
[10] Pursuant to part 3 of the request.
[11] The period identified in the request for which the information is sought.

but cannot do so for those who received ATG treatment without accessing patient records. Specifically, he says that UHN was able to provide the data for how many people received a bone marrow transplant for aplastic anemia and how many of those are deceased,[12] and that there should be no difference for the information that he is requesting about those treated with ATG.

[25] The appellant says that his request for only the number of people that died within 100 days of, and 100 days after, receiving ATG does not link the causes of death to the disease. He also says that, while there may be no further records for patients no longer being treated at UHN, there would be a record of their deaths if they were being treated for aplastic anemia between January 1, 2014 and October 13, 2019 and died while a patient at UHN. In other words, the appellant appears to concede that UHN would only have this information for individuals who died while they were a patient at UHN.

[26] Under parts 7 and 8 of the request, the appellant submits that he seeks access to a "copy of the protocol, procedure or common practice for [cyclosporine] when being administered post bone marrow transplant to prevent GVHD" (Graft vs Host Disease), and information about dosages, drug interactions and therapeutic ranges. The appellant says that the information he got from hospital staff about therapeutic ranges for cyclosporine changed, and that because fluctuations in his wife's levels of cyclosporine were documented in her medical records, they would also be documented in other patient records. However, the appellant submits that he is not seeking access to confidential information, but only to "statistical information to show if there is or isn't an issue with the maintaining of therapeutic levels [of cyclosporine]."

[27] Specifically, the appellant says that he seeks data for a specific time period that would show the number of post-bone marrow transplant patients for whom efforts were made to keep their cyclosporine levels in a therapeutic range, and the number where such efforts were not made; and the number of occasions where dosages were changed for those patients whose levels were not kept in a desired therapeutic range. Finally, the appellant wants to know the number of occasions where patients were kept in the therapeutic range and did not have their dosages changed, and also how many did.

[28] The appellant submits that he has been misinformed by UHN and has received conflicting and contradictory information, which resulted in his wife's inability to make informed treatment decisions. He says that he recorded conversations with hospital staff that contradict information about cyclosporine provided to him by the drug's manufacturer, show that his wife's dosages were inconsistent, and that PMH failed to comply with dosing policies. He also says that UHN treatment policies were breached and that in some instances, staff claimed to be acting in accordance with policies that

[12] This information was provided in response to part 2 of the request. Part 2 of the request seeks the same information as part 3, except for recipients of bone marrow transplants; that is, number of bone marrow transplant recipients during the period set out the request, and the number that died within 100 days of, and 100 days after, receiving a bone marrow transplant.

UHN's decision letter says do not exist.

Reply and sur-reply representations

[29] I invited UHN to submit representations in reply to the appellant's specific questions and comments and to explain why it could locate mortality statistics for recipients of bone marrow transplants but not ATG.

[30] UHN submitted an affidavit sworn by its FOIC, who communicated with the appellant in response to the request and during the appeal to the IPC, and who UHN submits has personal knowledge of the matter.

[31] According to the affidavit, the FOIC contacted the senior director of pharmacy, the clinical director, the unit manager, operations manager, the coordinator, administrative manager of UHN's statistical department, and the individual physicians involved as part of its searches. UHN says that all of these staff undertook searches of their working papers, correspondence, policies, guidelines, and departmental resources. The FOIC also searched UHN's corporate intranet site for responsive records.

[32] UHN says that when the appellant contacted the FOIC with concerns that further information should exist, the FOIC asked staff to conduct another search of their records. This resulted in the location of one more protocol that UHN then disclosed to the appellant in full. UHN says that, after the appellant provided new information to the IPC mediator, the FOIC circulated it to the same staff, but that all of them indicated that they were not able to locate any more records.

[33] UHN says that it simply does not have the statistical data requested and that responsive information (including statistics it does track) has already been disclosed to the appellant. UHN explains that the figures provided to the appellant were taken "from the Cancer Registry Report and data collected by UHN's transplant unit."

[34] UHN says that it does not maintain the more detailed data the appellant is requesting. It says that, to collect this data, it would need to assemble a list of all patients that fall within the parameters required, conduct a review of each patient's medical chart, and then produce a report based on the findings. UHN says that this would not consider that patients may have continued treatment at other locations or may have passed away due to other causes. In any event, UHN submits that it is prevented by *PHIPA* from accessing patients' medical charts in this manner in order to respond to the appellant's access request under *FIPPA*.[13]

[13] UHN refers to section 37(1) of *PHIPA*, which sets out circumstances in which a health information custodian may use personal health information without consent. It is not necessary for me to address this argument to decide the issue before me, which is whether UHN has fulfilled its obligations to conduct a reasonable search under section 24 of *FIPPA.* Other than preserving the right of access under *FIPPA* to records of personal health information that have been appropriately severed (section 8(4) of *PHIPA*), *PHIPA* has no application to this appeal under *FIPPA*. There is no dispute that the appellant does not

[35] Finally, UHN says that its clinical team was consulted and explained that it tracks and conducts research on allogeneic stem cell transplants, which is why it was able to provide specific data for these cases. UHN says that, although they were able to identify the number of patients who underwent alternative treatment, their mortality rates were simply not tracked or recorded.

[36] In his sur-reply representations, the appellant says that aplastic anemia "is not a cancer of any kind" and questions why information about it would be captured in a cancer registry report, or why information about one treatment, but not another, would be captured. He submits that the information "does exist and is available for disclosure," but is being deliberately withheld, and that this is the type of "stonewalling" that led to the access request.

Analysis and findings

[37] I am satisfied that UHN's search for responsive records was reasonable.

[38] As mentioned above, UHN is not required to prove with certainty that further records do not exist in order to satisfy the requirements of *FIPPA*. It must only show that it has made a reasonable effort to locate responsive records. Based on the evidence before me, I find that it has. UHN's representations demonstrate that experienced employees, knowledgeable in the records related to the subject matter of the appellant's request, made reasonable efforts to locate responsive records. UHN identified the staff that were asked to search, in the various relevant departments, and described their search efforts and the results.

[39] Parts 3, 7 and 8 of the request seek access to specific statistics over a discrete period of time, including about drug dosage fluctuations and monitoring. As also noted above, although an appellant will rarely be in a position to indicate precisely which records have not been identified in an institution's response, the appellant must still provide a reasonable basis for concluding that such records exist. In the circumstances, there is insufficient evidence upon which to conclude that UHN tracks all of the specific data sought by the appellant, and I accept UHN's explanations that it does not, and why.

[40] Regarding part 3 of the request, I accept UHN's explanation that it was able to provide mortality rates for bone marrow transplant recipients because it tracks and conducts research on allogeneic stem cell transplants, but does not track or record death rates for patients who underwent treatment with ATG. The appellant's position appears to be that, if discrete mortality statistics are not held by UHN, then they can be found in sources such as patient's medical records. The appellant does not seek access to individual patient information, only that UHN extract the information from patient records, and compile and disclose it to the appellant as a statistic. However, previous IPC orders have found that, as a rule, section 24 of *FIPPA* does not require institutions

---

have a right of access to patient records under *PHIPA*, and there is no privacy complaint under *PHIPA* before me.

to create a record in response to an access request if one does not currently exist.[14] I have accepted UHN's explanation that it does not track the specific statistics sought, and I agree with and adopt the reasoning in those past IPC orders. There is no dispute that UHN is an institution under *FIPPA* and that the appellant has made an access request under *FIPPA* (or that *PHIPA* does not, in any event, provide for a general right of access to personal health information).[15]

[41] With respect to part 7 (for information about the therapeutic range of cyclosporine after a bone marrow transplant, and about maintaining or deviating from the therapeutic range), UHN explains that the therapeutic range for cyclosporine depends on certain indicators and treatment goals, and that no data is available regarding the number of patients whose levels fell outside of the therapeutic range when tested, or patients whose levels were within the therapeutic range but had their dose changed.

[42] As for part 8 (for information about whether patients are treated more frequently with cyclosporine if they are found to be out of range or have dosages adjusted, and for access to a related protocol, procedure of common practice), UHN states that the frequency of testing depends on the time from transplant and the stability of the patient's clinical situation.

[43] The appellant submits that information responsive to parts 7 and 8 is available in his wife's patient record, but that it relates to her only, while he seeks access to statistical data for *all* post-bone marrow transplant recipients of cyclosporine to observe trends in monitoring of the drug's therapeutic levels and dosing. According to UHN, however, drug dose monitoring and changes are dependent on individual clinical situations. I accept UHN's position that monitoring of drug dose fluctuations and adjustments are a matter of individual treatment and that, after consultation with its pharmacy and statistics department, as well as individual physicians with knowledge of the matter, UHN's search revealed that it does not maintain the specific data requested in any aggregate form.

[44] In these circumstances, I am not persuaded that there is a reasonable basis on which I could conclude that additional responsive records exist that contain the specific statistics sought by the appellant about monitoring of therapeutic levels, dose changes and fluctuations relating to cyclosporine, or that UHN maintains the particular statistical data sought by the appellant. I note that UHN granted access to a specific protocol in response to parts 7 and 8 of the request. Given the specificity of the request, however, I also accept UHN's explanation that recorded information that answers all of the appellant's unique questions may not exist and that, some of the information (such as drug dose changes and monitoring for individual patients) is simply not tracked and collated, but rather is a matter to be discussed with a patient's individual treating doctor.

---

[14] Orders P-50, MO-1381, MO-1442, MO-2129, MO-2130, PO-2237, PO-2256, MO-2829 and PO-3928.

[15] *PHIPA* gives individuals or their substitute decision makers a right of access to their own personal health information (and, in limited circumstances, to others on the individuals' consent).

[45] Based on all of the material before me, I am satisfied that the employees who searched for responsive records are knowledgeable in the subject matter of the request, and that they expended reasonable efforts to locate records that are reasonably related to the request, with the result that all but limited portions of the 14-part request were answered. I accept UHN's evidence that individuals as well as relevant teams were consulted, and that the individuals, clinical teams and the pharmacy department would be familiar with the statistics that they do or do not maintain, including information about the administration of cyclosporine. Finally, I accept that the FOIC who coordinated the search understood UHN's responsibility to conduct a thorough search and that UHN located and disclosed records responsive to the request. I also conclude that, where an institution has demonstrated that it does not maintain certain data and that a responsive record does not currently exist, the institution is not obligated to create a record.

[46] Therefore, for the reasons outlined above, I find that UHN conducted a reasonable search for responsive records in compliance with its obligations to do so under *FIPPA*. I uphold the search and dismiss this appeal.

ORDER:

I uphold UHN's search as reasonable and dismiss this appeal.

Original signed by: March 29, 2022

Jessica Kowalski
Adjudicator