Information and Privacy Commissioner,
Ontario, Canada

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

PHIPA DECISION 223

Complaint HA22-00173

The Hospital For Sick Children

August 25, 2023

Summary: The complainant made a correction request under the *Act* to the hospital. The complainant asked that a record relating to the genetic testing of his minor child and all references to it be removed in their entirety from the child's records of personal health information. In this decision, the adjudicator finds that the hospital does not have a duty to correct the record under section 55(8) by upholding its refusal to correct based on the application of section 55(8) itself. She also finds that the complainant's request that the record be removed from the child's health record is not a remedy that is available under section 55(10) or any other section of the *Act*. The complaint is dismissed.

Statutes Considered: *Personal Health Information Protection Act, 2004*, S.O. 2004, c.3 sections 55(8) and 55(10).

Decisions Considered: PHIPA Decisions 125, 162, 171 and 207.

BACKGROUND:

[1] This decision resolves the sole issue raised as the result of a complaint of a decision made under the *Personal Health Information Protection Act* (the *Act*) by the Hospital for Sick Children (the hospital) in response to a correction request. The requester's correction request to the hospital was that it remove a record of genetic testing conducted on his child, including the test results, from all health records belonging to the requester's minor child. The requester's reason for the request was his view that the genetic test was based on assumptions and is not an established

confirmatory diagnostic test.

[2] In response to the correction request, the hospital issued a decision to the requester, denying the correction request under sections 55(9)(a) and 55(9)(b) of the *Act*. With respect so section 55(9)(a), the hospital advised the requester that the genetic test result was not completed at the hospital and, therefore, the hospital did not have the authority to correct the record and must refuse the correction request. Regarding section 55(9)(b), the hospital advised the requester that the correction request was also being denied because the genetic test results contained professional opinions or observations that were made in good faith. The hospital advised the requester that he was entitled to have a Statement of Disagreement (SOD) attached to his child's health record and to forward the SOD to the hospital if he so wished.

[3] The requester (now the complainant) subsequently wrote to the Information and Protection of Privacy Commissioner of Ontario (the IPC) advising that he wished to file a complaint with respect to the hospital's decision.

[4] During the mediation of the complaint, the complainant advised the mediator that he believes that the information contained in the genetic test is inaccurate. The complainant expressed great dissatisfaction with the care provided to his child because of the reliance on the results of the genetic test, among other concerns. The complainant was disappointed with the option of attaching a Statement of Disagreement to his son's chart.

[5] Also during mediation, the hospital confirmed its previous decision to deny the correction request under sections 55(9)(a) and (b) of the *Act*. The complainant confirmed that he wants the hospital to correct his child's health record by removing the genetic test from their record of personal health information.

[6] The parties do not dispute that the hospital is a health information custodian as defined in section 3(1) of the *Act*.

[7] The complaint then moved to the adjudication stage of the complaints process where an adjudicator may conduct a review. I sought and received representations from both the complainant and the hospital.

[8] For the reasons that follow, I find that the hospital does not have a duty to correct the record under section 55(8). I uphold the hospital's refusal to correct based on my finding that the complainant has not established that the information is inaccurate for the purpose for which it is used. I also find that the complainant's request that the record and all references to it be removed from his child's health records is not a remedy that is available under the *Act*. I dismiss the complaint.

RECORD:

[9] The record at issue is a report setting out the results of genetic testing which was conducted at, and authored by, an out-of-country laboratory, as well as all references to the results in the child's records of personal health information.

DISCUSSION:

[10] The sole issue in this complaint is whether the hospital has a duty to make the requested correction by removing the genetic testing record and all references to it from the child's records of personal health information.

[11] The purposes of the *Act* are set out in section 1, and include the right, at paragraph (c):

> to provide individuals with a right to require the correction or amendment of personal health information about themselves, subject to limited and specific exceptions set out in [the *Act.*]

[12] Section 55(8) of the *Act* provides for a right of correction to records of an individual's own personal health information in some circumstances. It states:

> The health information custodian shall grant a request for a correction under [section 55(1) of the *Act*] if the individual demonstrates, to the satisfaction of the custodian, that the record is incomplete or inaccurate for the purposes for which the custodian uses the information and gives the custodian the information necessary to enable the custodian to correct the record.

[13] Section 55(9) of the *Act* sets out exceptions to the duty to correct records. In this review the hospital relies on the exception at section 55(9)(b) to deny the requested corrections. This section reads:

> Despite subsection (8), a health information custodian is not required to correct a record of personal health information if,
>
> > (a) it consists of a record that was not originally created by the custodian and the custodian does not have sufficient knowledge, expertise and authority to correct the record; or
> >
> > (b) it consists of a professional opinion or observation that a custodian has made in good faith about the individual.

[14] Read together, these provisions set out the criteria pursuant to which an individual is entitled to a correction of a record of his or her own personal health

information. The purpose of section 55 of the *Act* is to impose a duty on health information custodians to correct a record of an individual's personal health information where the record is inaccurate or incomplete for the purposes for which the custodian uses the information, subject to the limited and specific exceptions set out in section 55(9) of the *Act*.

[15] Section 55(10) states that upon granting a request for a correction, the health information custodian shall make the requested correction by recording the correct information in the record and striking out the incorrect information in a manner that does not obliterate the record. There is no right in the *Act* to have the incorrect information in a record removed, replaced, or amended in such a manner that the incorrect information is completely obliterated—it must remain legible.

[16] Therefore, even if the IPC were to order that information in a record be corrected, the order can only require a custodian to strike out the incorrect information in such a way that the original entry remains legible.

Representations

[17] The hospital's position is that it does not have a duty under section 55(8) to make the requested correction because the request falls under both exceptions found in sections 55(9)(a) and 55(9)(b). Alternatively, the hospital argues that the complainant has not satisfied the requirements of section 55(8). The hospital submits that while the complainant has stated his disagreement with the results of the genetic test, he has not discharged his burden to establish that part of the record is incomplete or inaccurate for the purposes in which the hospital used the information because he has not provided any evidence that the genetic test results are incomplete or inaccurate.

[18] The hospital submits that the exception in section 55(9)(a) applies because the genetic test results are not contained in a record that it originally created and it does not have sufficient authority to correct the record.

[19] The hospital's position is that the exception in section 55(9)(b) also applies. In this regard, the hospital states:

> Although the genetic test was performed at an institution outside of SickKids, interpretation of the genetic test result, and its relevance to future care, requires special knowledge and expertise that the relevant SickKids professionals possess. The references to the genetic test results that are made throughout the Patient's chart qualify as professional opinion or observation.
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> . . . The onus is on the Complainant to establish that the "professional opinion or observation" was not made in good faith. The Complainant has not provided any evidence to support such an assertion. Therefore, there

> are no reasonable grounds to conclude that the professional opinions or observations were made in bad faith.

[20] Finally, the hospital submits that the complainant provided a Statement of Disagreement, and that all reasonable efforts were made to disclose that statement to the relevant health care providers at the hospital, as well as external health care providers to whom the hospital provided information which referenced the genetic test results.

[21] The complainant submits that the hospital has a duty under section 55(8) to make his requested correction because the genetic test results in his child's health records are "false and inaccurate." The complainant further submits that the research lab where the genetic test was conducted stated in its report that the genetic test was not a "confirmatory test," and there are no functional studies to conclusively prove the test results.[1]

[22] The complainant goes on to argue that the because the information in the record is false and inaccurate, the exceptions to the duty to correct in sections 55(9)(a) and 55(9)(b) do not apply. With respect to section 55(9)(a), the complainant submits the hospital is responsible for its actions and must evaluate the facts based on universally accepted principles of medical science. The complainant further submits that when it was identified and brought to the hospital's attention that the lab that conducted the genetic testing stated in the report that the results were non-conclusive/incomplete, the hospital cannot now make a "layperson's claim" that they are not responsible simply because the lab wrote the report. The complainant's position is that the hospital must independently evaluate the errors in the report and is responsible for correcting the record in their possession.

[23] Regarding section 55(9)(b), the complainant submits that it does not apply because the concept of "professional opinion or observation" cannot not apply to the results of genetic testing. For example, the complainant submits that a genetic mutation result is not something that can be professionally observed and does not comprise a professional opinion.

[24] Having met the criteria for correction to his child's health record, the complainant submits, the form of correction that he seeks is the complete removal of the genetic test results from all of his child's health records because of the hospital's duty to remove this information.

Analysis and findings

[25] For the reasons stated below, I find that the complainant has not discharged the onus in section 55(8) of establishing that the hospital is required to make the requested

[1] The complainant also submits that genetic testing can only be done with informed consent, and that the consent he provided was not informed.

correction.

[26] Section 55(8) requires the complainant, as the individual asking for the correction of the genetic testing record and all references to it in his child's health records, to demonstrate to the satisfaction of the hospital that this information is inaccurate for the purposes for which the hospital uses the information. In addition, section 55(8) requires the complainant to give the hospital the information necessary to enable the hospital to correct the record. Both conditions must be met for the onus to be discharged.

[27] I find that the complainant has not done this. The only information that the complainant has provided to the hospital about his requested correction is his assertion that the results of the genetic testing are false and inaccurate. The hospital takes the position that the complainant's assertion does not demonstrate to its satisfaction that the record is incomplete or inaccurate for its purposes.

[28] I agree with the hospital's position. The complainant has neither provided evidence to support his assertion that the record he wants corrected is inaccurate for the purposes for which the hospital uses the information nor has he provided the information necessary to enable the hospital to correct the record. The complainant's assertion, with nothing more, is not sufficient to satisfy his onus under section 55(8) of *PHIPA*. Accordingly, I find that the complainant has not established that section 55(8) of *PHIPA* applies and, as a result, the hospital is not required to grant his correction request.

[29] Having found that the requirements of section 55(8) were not met, it is not necessary for me to consider whether the exceptions to section 55(8), found in sections 55(9)(a) and (b) apply.

[30] Lastly, as previously stated, the complainant's request is that all references to the results of the genetic testing, including the report itself, be removed from his child's records of personal health information. Section 55(10) states that upon granting a request for a correction, the health information custodian shall make the requested correction by recording the correct information in the record and striking out the incorrect information in a manner that does not obliterate the record. There is no right in the *Act* to have the incorrect information in a record removed, replaced, or amended in such a manner that the incorrect information is completely obliterated—it must remain legible.

[31] Therefore, even if the IPC were to order that information in a record be corrected, the order can only require the hospital to strike out the incorrect information in such a way that the original entry remains legible. Therefore, the removal of the results of the genetic testing from the child's health records, including the report itself, is not a remedy that is available under section 55(10). There is no authority in the *Act* for me to grant the remedy the complainant seeks.

NO ORDER:

1. For the foregoing reasons, no order is issued and I dismiss the complaint.

Original signed by: August 25, 2023

Cathy Hamilton
Adjudicator