

Frequently Asked Question: Can MGL coordinate sending a de-identified patient sample for genetic testing at a non-Canadian lab?

Summary:

Yes, but there is an increased risk for sample mix-up/mis-identification, extra work is required on the part of both the laboratory and the requesting physician, and there are limitations.

Background:

The Freedom of Information and Protection of Privacy Act (FIPPA) of British Columbia prohibits the disclosure of personal information outside Canada without the individual's informed consent; signed record of the individual's consent is also a requirement.

A de-identified sample has all identifiers, which would allow re-identification of a specific individual, removed (e.g., name and/or personal health number; date of birth (DoB) and gender may fall into this category if the pool of potential individuals is sufficiently small).

MGL can generate sample-specific patient identifiers to be used as an alternative to name and PHN. However, laboratory quality standards and regulations in many non-Canadian labs require that DoB and gender must also be associated with the sample. These steps require extra processing on the part of MGL. Although the risk of sample mix-up in MGL is low, sample de-identification also increases the risk of mix up.

The referring health care provider is responsible for:

- 1) Ensuring the referral laboratory will accept de-identified samples, and confirming their requirements for such requests;
- 2) Obtaining the substitute patient identifiers from MGL *in advance* of requesting sample shipment as all paperwork to be forwarded with the sample must be appropriately completed with the substitute identifiers before being faxed to MGL (including the MSP approval letter);
- 3) Re-identifying the report received from the external laboratory;
- 4) Submitting the re-identified report and invoice to MSP, as a personal health number (PHN) is required to authorize payment to the out-of-province laboratory for testing services.

Therefore, requests for de-identified sample shipment also increase the chance of mis-identification of reports and increase the work required by the requesting health care provider.

In view of all of the aforementioned issues, requests for de-identified shipments are not encouraged by MGL. Nonetheless, in general, ***following consultation with MGL***, requests for de-identified shipments can be accommodated, except in the following circumstances:

- The external laboratory is not willing to accept a de-identified sample.
- The patient is paying for the testing privately.
- The test requested may alter the management of a pregnancy (whether of the patient requesting de-identified shipment **or** a different family member) and, therefore, involves or will/could involve the shipment of a prenatal specimen.