

FAQ About DNA Banking at the Roy Romanow Provincial Laboratory (RRPL)

Question: What is DNA banking and why is it needed?

Answer: DNA banking at the RRPL refers to the extraction and storage of genetic material from blood for medically indicated genetic diagnostic purposes only. In other words, we are taking DNA out of the blood cells so that we can use it to perform diagnostic genetic tests. Banking of this DNA can fall under three categories:

- 1) Short-term only for the test ordered and after testing is complete any remaining DNA sample destroyed.
- 2) DNA banking to help family members only if we need to compare a family member's result to yours to ensure we have the correct answer.
- 3) DNA banking to help test validation this would allow the RRPL to use your anonymized sample (name removed) to help us offer other genetic tests to help other patients in the province.

Question: What samples get DNA banked?

Answer: All samples are stored for a minimum of one year to ensure that all required testing has been completed. In rare cases, retesting may be needed to ensure a quality result. DNA banking for longer then this testing period needs explicit and documented patient consent, which is obtained by the ordering health care provider at the time of the initial blood draw.

Question: How is consent for long-term DNA banking given?

Answer: It can only be given by the patient or their guardian at the time the testing is ordered by their health care provider. Documentation of this consent is signed off by a physician or genetic counsellor on the RRPL molecular genetics lab requisition form. (Requisition can be found here)

Question: Who is responsible for obtaining consent?

Answer: The consent process is the responsibility of the health care provider at the time that they are explaining the genetic testing to the patient or their guardian. The RRPL lab will do its best ensure that information is in the patient's medical record regarding the length of DNA storage, how to request that the DNA sample be disposed of, and how to request that the DNA be stored longer. Questions can be answered by e-mailing the Genetic Resource Centre GRC@saskhealthauthority.ca

Question: What is the intended use of this DNA Bank?

Answer: The banked DNA will only be used for medically-indicated genetic testing that is being requested by a qualified health care provider for the care of that individual or their family. Stored samples including banked DNA will not be used for secondary purposes, including testing for other conditions, genes or markers outside of the provided consent. When an individual consents for their DNA to be used for test validation, this is consent to validate a genetic test performed at a provincial laboratory in Saskatchewan, but only for the condition that they originally consent to. This means that banked DNA will not be used for private research projects, to validate a medical test for a condition that that patient has not been previously tested for, or for testing with regard to criminal investigations.

Question: What is the policy for this DNA bank when it comes to research?

Answer: Only samples that have been consented for use in method validation - as indicated on the requisition - can be used for research. This consent is not permission for the DNA sample to be used in other types of medical research. Without exception, banked DNA can only be used for method validation based on the clinical indication for which the sample was submitted and as approved by a health care provider and it would not be consent to use the sample to help validate tests for conditions or symptoms that the individual was not previously tested for. It is not the intention of the RRPL DNA banking policy to perform unlimited genetic testing on anonymized banked DNA samples to ensure that the RRPL stays within compliance of their ethical commitments.

Question: Has this DNA banking process undergone ethics review?

Answer: Yes.

Question: Who has direct access to my sample?

Answer: Only medical laboratory professionals who work in the Molecular Laboratory Department at the RRPL have direct access to the DNA bank. These medical professionals work in accredited institutions and are bound by the policies of the RRPL.

Question: Will this DNA bank increase my exposure to the police or result in any legal consequences?

Answer: No. This DNA is treated like any clinical specimen collected for medical purposes. Banked DNA is only to be used for clinical testing as ordered by a physician in accordance with appropriate medical care. This DNA bank is not open to the public and cannot be used or searched by law enforcement as has occurred with some publicly available genealogical websites.

Question: How securely is my DNA stored?

Answer: The blood is collected and transported with the same security as other medical samples. Once the DNA is banked it is kept 24-hour security. The general public will never have access to the DNA bank, as it is located behind several locked doors and monitored for any breach of that security.

Question: Can I get my DNA destroyed if I changed my mind on consent to bank?

Answer: Yes. Please contact the Genetics Resource Centre <u>GRC@saskhealthauthority.ca</u> and your banked DNA will be destroyed once we have written permission instructions to do this – we have a form that needs to be filled and signed.