

Information about the storage of DNA variants in the LUMC Varda database

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Summary

- To perform a reliable DNA test, we compare your DNA variants with those of others.
- Therefore, the LUMC stores DNA variants in a special database.
- University hospitals in the Netherlands are allowed to access each other's databases.
- Your name is not in the database.
- Only the LUMC can determine whether a DNA variant belongs to you.
- The database is as secure as possible and can be accessed by a small number of people online.
- If you wish to object, you can do so (see below).

How does DNA diagnostics work?

A DNA test examines your DNA. Dozens to millions of variations are found in your DNA, depending on the type of test. We call these DNA variants. With DNA diagnostics, we determine which of the DNA variants is the cause of a condition.

The primary way we do this is by comparing your DNA variants with the DNA variants of other people. The larger the number of people we compare, the smaller the chance we draw incorrect conclusions about a DNA variant in your case.

That's why we store the DNA variants of everyone who receives a DNA test indefinitely in a secure database at the Clinical Genetics department of the LUMC. This database is called Varda, which stands for Variant Frequency Database.

Before we store your DNA variant in the database, we assign it a code. Your name or patient number is therefore not stored in the database. Only your healthcare provider can link the DNA variant to you using this code.

The coded DNA variants in the database are available to the Clinical Genetics departments of the Dutch University Medical Centers (UMCs). The UMCs use these variants in the DNA diagnostics of new patients. The DNA variants in the database are not used for any other purpose.

How does this work?

Suppose a variant is found in a patient about which little is known. The Varda database and DNA databases of other university medical centers in the Netherlands are then checked to see if this variant has been found in other patients before. If so, the patients' symptoms are compared by their healthcare providers. The identity of the patients is, of course, not disclosed. If the symptoms are similar, it becomes more likely that the found variant is the cause. Conversely, if the symptoms are very different, or the DNA variant occurs much more frequently than expected, the chance that the found variant is the cause of a patient's symptoms becomes much smaller.

What's in it for you?

Because we work this way, we can also provide you with the best (genetic) care. Without using DNA variants stored in the Varda database, there is a much greater chance that we will overlook variants that cause medical symptoms. Conversely, this can also result in us wrongly identifying harmless variants as the cause of medical symptoms.

Is there a risk?

The database is accessible to a very limited number of people. It is stored on a server at the LUMC and is not (publicly) accessible online. Only authorized UMC employees can access the database from their own workstations. Data that can be directly traced back to you, such as your name, address, or patient number, is not stored in the database. We also take the necessary security measures to ensure that the data in the database is stored as securely as possible.

Objections

If you object to the use of your DNA variants for the diagnosis of other patients, you can indicate this by sending an email to genoomdiagnostiek@lumc.nl. We will then remove your data from the database.

Other questions?

Do you have any questions after reading this information? Please contact the person who requested the DNA test or a physician at the Department of Clinical Genetics at Leiden University Medical Center (LUMC) at +31 71 526 8033 or genetica@lumc.nl. For more information about the department, see <https://www.lumc.nl/org/klinische-genetica/>.

More information about your privacy rights can be found at <https://www.lumc.nl/privacyrechten/>. If you have any further questions about the protection of your privacy, please contact our Data Protection Officer at the LUMC at privacy@lumc.nl.