

Pathology testing

What happens to your data?

This leaflet provides information about the testing of small amounts of tissue or cells ('samples') removed from your body. The tests are carried out in a pathology laboratory. The leaflet also explains what happens to your data after the tests have been done.



Your GP or specialist removes a small piece of your skin or some other tissue or cells, for testing.

The sample is sent to a pathology laboratory for testing.

The sample is prepared for testing. This involves embedding it in transparent wax in the form of a small block.

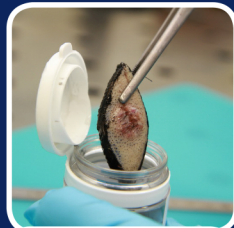
A very thin 'slice' is removed from the block. A pathologist then examines the slice under a microscope.

The pathologist (medical specialist) makes a diagnosis.

GP/specialist



Skin/tissue/
cell sample



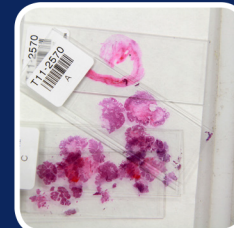
Pathology
laboratory



Embedded tissue
sample



Microscopic
examination



Diagnosis by
pathologist



Pathology testing: The process

Seeing your data and saying
what can be done with it

The pathologist sends the results of the tests to your GP or specialist, who will then discuss the results with you.

Pathology laboratory



Data

1. Data records at the laboratory

All the details of your sample are saved on the pathology lab's computer system. The system is protected, so that only pathologists and other authorized staff can access the data.

2. Retention of samples

Sample blocks are saved in a block archive. It is important that your sample is retained so that it can be re-examined later. This might be necessary to help your doctor make treatment decisions, or if more than one health problem is detected. Sometimes blocks are also used in scientific research. The use of samples for research is described in the leaflet Nader gebruik van weefsel (What tissue samples can be used for).

3. Retention of data in the national system

Summarized information about your test is saved on PALGA's national computer system. Security of this system is very tight and meets all the relevant legal requirements. Regular checks are carried out on the system and PALGA is registered with the Data Protection Authority (CBP). All pathology laboratories in the Netherlands send data to PALGA.

PALGA

The information recorded on the PALGA system includes:

- Test results
- Name of the testing laboratory
- Subject's gender and date of birth

All personal data, such as your surname, is encrypted so that it cannot be read. Encryption happens automatically when the information is sent to PALGA.

The pathologist

A pathologist can only retrieve your data from PALGA if he or she is involved in your treatment. PALGA staff are not involved in the process of retrieving data.

Scientific research

There is a Privacy Committee, which decides whether PALGA data can be released for scientific research. The committee is made up of pathologists, lawyers and representatives from patient organizations. If a request to use data for scientific research is approved, the data is made available to the researcher by PALGA staff with special authorization. PALGA never releases personal data to researchers. In fact, that would be impossible, because all the personal information on the system is encrypted. From the data recorded on the PALGA system, researchers can see where to find samples from patients with a given medical condition, but access to the stored samples is carefully controlled. The use of samples for research is described in the leaflet Nader gebruik van weefsel (What tissue samples can be used for).

Requesting data from PALGA

Privacy

All the rules relating to the protection of privacy are documented in an official set of regulations. This is composed of a set of regulations concerning the use of data by pathologists and a set of regulations concerning the use of data by researchers. Both sets of regulations are available from PALGA on request. For privacy complaints regarding PALGA's services, please contact our Data Protection Officer at DPO@PALGA.nl.

PALGA



PALGA was set up in 1971. The archive contains all the data submitted by pathology laboratories since then. Only test data is kept, not the actual samples. All personal information, such as your surname, is encrypted so it cannot be read. Encryption occurs automatically when the data is sent in.

Pathologisch Anatomisch Landelijk Geautomatiseerd Archief

Dutch pathology registry

How PALGA adds value

1. Less testing

It may be that a sample has been taken from you in the past for testing at a pathology lab. If so, the data will already be on the PALGA system and the old test results and the new results can be compared easily, giving the pathologist a better picture of your health and any changes in your condition. This means that further tests are less likely to be needed.

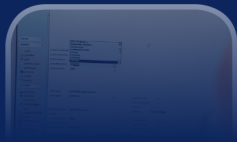
2. Better treatment

Comparing previous test results with new ones can help doctors and pathologists make more definite or accurate diagnoses. That means better treatment for patients.

3. Scientific research

The data kept by PALGA is very useful for scientific research, because the archive includes data on all sorts of medical conditions. Research can help identify the causes of disease, and the more doctors and scientists know about the causes of disease, the more they can do to treat it. PALGA also works frequently with the National Cancer Registry.

Seeing your data and saying what can be done with it



Seeing your data

If you have had a pathology test done and you would like to know whether any data about you has been stored on the PALGA system, you should contact your specialist or GP. He or she will then put you in contact with the pathology lab.

Saying what can be done with your data

For example, you can ask specifically:

- for your data not to be made available to other pathologists in the future; and
- for your data not to be used for scientific research.

Finally, you can ask for previous data about you to be deleted from the PALGA system. This can be arranged through the pathology lab where your sample was tested. Removing data could make it more difficult to arrive at an accurate diagnosis in the future, as your file would be incomplete.

Children

Up to the age of twelve, a child needs a parent or guardian to speak on his or her behalf. For example, a request for data relating to a child not to be recorded on the PALGA system has to come from a parent or guardian.

A child aged twelve to fifteen is considered able to make independent decisions as a patient. This means that children in this age group can say for themselves what can be done with their data.

From the age of sixteen, the person is regarded as an adult in medical situations. The general information in this leaflet therefore applies to sixteen and seventeen-year-olds.

Use of samples for scientific research

There is a separate leaflet – Nader gebruik van weefsel (What tissue samples can be used for) – which provides additional information about the retention of samples and their use for scientific research. The leaflet is available from your hospital or GP. It can also be downloaded from the PALGA website or the Dutch Pathology Association website.

www.palga.nl and www.pathology.nl