Leiden University Medical Center
Section Genome Diagnostics, **Department of Clinical Genetics**

GIVE THIS PART TO THE PATIENT

Information for patients regarding the secondary use of tissue

Your biological tissue (e.g. blood, urine, skin, mouth swabs, CVS /amniotic fluid) has been used for chromosomal, DNA or biochemical research for a particular disorder. After completion of diagnostic procedures and testing there is generally a small amount of material remaining that is not simply destroyed. This is referred to as '*residual material'*. This residual material is often used for scientific research into your condition, and almost all knowledge about health and disease is acquired through medical scientific research.

This research may occur in several ways, such as through study of a single patient, through the comparison of data from a group of patients with other patients or healthy persons or, frequently, through studies in a research laboratory. In much of this research, residual patient material is used. Use of this material occurs in a coded manner, with the researcher unaware of the identity of the patient and thus unable to directly trace it to a specific individual. Only the person who gave the material to the researcher has a key to the code and is aware of the identity of the treating physician. Within the laboratory one person is designated to apply and carry responsibility for a unique code.

If it is necessary for the research that the researcher knows the identity of those involved - the material is thus traceable - your *specific permission* is required and this will be requested and discussed with you in advance.

It occasionally happens that a researcher discovers something of direct importance to a particular patient. Should this occur, the person who has the key to the code will inform your doctor, who will then discuss this information with you.

What should you do?

- You do not have to do anything if you do *not object* to the use of your residual biological material for research in which the researcher does *not have access to your personal data*.
- If you *do object*, you can discuss this with your doctor. This will be registered and passed on to the laboratory, so that the residual material is not used.
- If you have no objection and wish to be informed of results important to you or your family, you can also discuss this with your doctor.
- You will be contacted and informed in case of research in which the researcher must have *access to your personal details*. Your *written permission* is always needed for this type of research.

We hope that you now have sufficient information. The full text of this brochure is available in Dutch at https://elsi.health-ri.nl/sites/elsi/files/2022-01/Gedragscode_Gezondheidsonderzoek_2022.pdf