



In certain cases personal data which can identify you is required for specific research. In these situations your physician will contact you and ask for your permission. It is your choice whether you participate or not.

5.



Not all research projects can be anonymous

Some research projects require more personal information. In these cases, your physician will contact you with information about the specific project (in writing or during a visit) and allow you to decide whether you will participate or not. Your personal data will only be shared if you have given specific permission to do so.

Participation in research projects

Some research projects require specific groups of patients. In those cases, your physician may contact you to ask if you would like to take part. It is always your choice whether you participate or not. You will never be included in a research project without your knowledge and consent.

If you don't want to participate

Contact your physician if you have questions, or if you do not want your medical information to be made available. In that case your medical records will not be shared with researchers.

Opt out?

Let your physician know if you do not want your medical data to be made available for research.



Need additional information?

For more information, visit our website www.lumc.nl/elan. If you still have questions, feel free to email LUMC elan@lumc.nl or ask your physician.

Your medical data to improve healthcare

Your primary care physician is working with Leiden University Medical Center (LUMC) and other organisations to improve healthcare for you and for others in our community.



1.



Scientists from universities and other organizations conduct medical research into the treatment and prevention of diseases and risk factors.

Your physician's computer system

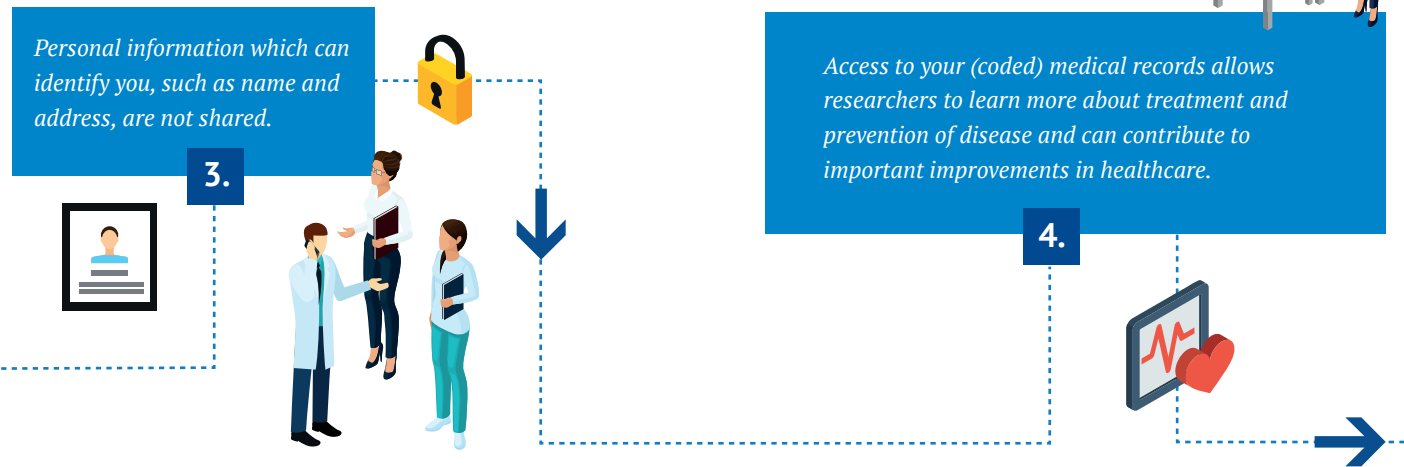
Your physician uses a computer system to store their patients' medical information. He/she would like to make an encoded copy of this information available for statistical and scientific research. Using this data, scientists from LUMC can conduct research which often leads to improvements in care and treatment.

Sample research topics

- Are there diseases that are very common in our area/ community? How can the physician respond to these diseases like depression, joint pain, certain infections?
- Are there groups of patients who have a higher risk of cardiovascular events? For example, is there a higher risk of heart disease in patients with depression who have less energy for physical activity?
- Are there certain groups among older people that are more likely to be admitted to hospital?
- How can we detect certain forms of cancer in an earlier stage? Which groups of people have a higher risk for these cancers?



Researchers are given access to an encoded copy of your digital medical records, which may be linked to other research databanks.



Who can see my medical data?

Your physician is working with researchers from the Public Health & Primary Care department at LUMC and LUMC- campus Den Haag. These researchers have formed a scientific, non-profit collaboration with STIZON and the PHARMO Institute. ELAN (Extramural Leiden Academic Network) is a collaboration network that aims to expand physicians' medical knowledge and skills, and to improve the quality of care outside the hospital.

Privacy

Medical data is confidential. Naturally you want your data to remain secure, and we have taken careful measures to protect the privacy of your data. Medical data from your file is encoded before it is shared - this means that there is no way for researchers to link the information back to you personally. Researchers do not see your name, your address, your date of birth, nor your physician's name.

What data is shared?

An encoded copy of data with information about your general health and treatment such as symptoms, diagnoses, prescriptions, consultations, referrals, measurements and results.

How can data be linked to other databanks?

Some research projects can require that various data sources are combined, for example, diagnoses with the National Cancer Registry (NKR). Where required, this is done via a trusted third party (TTP) who can link the personal information but cannot see the medical information connected to it. Researchers do not know who's data they are analyzing, they see only the encoded data.