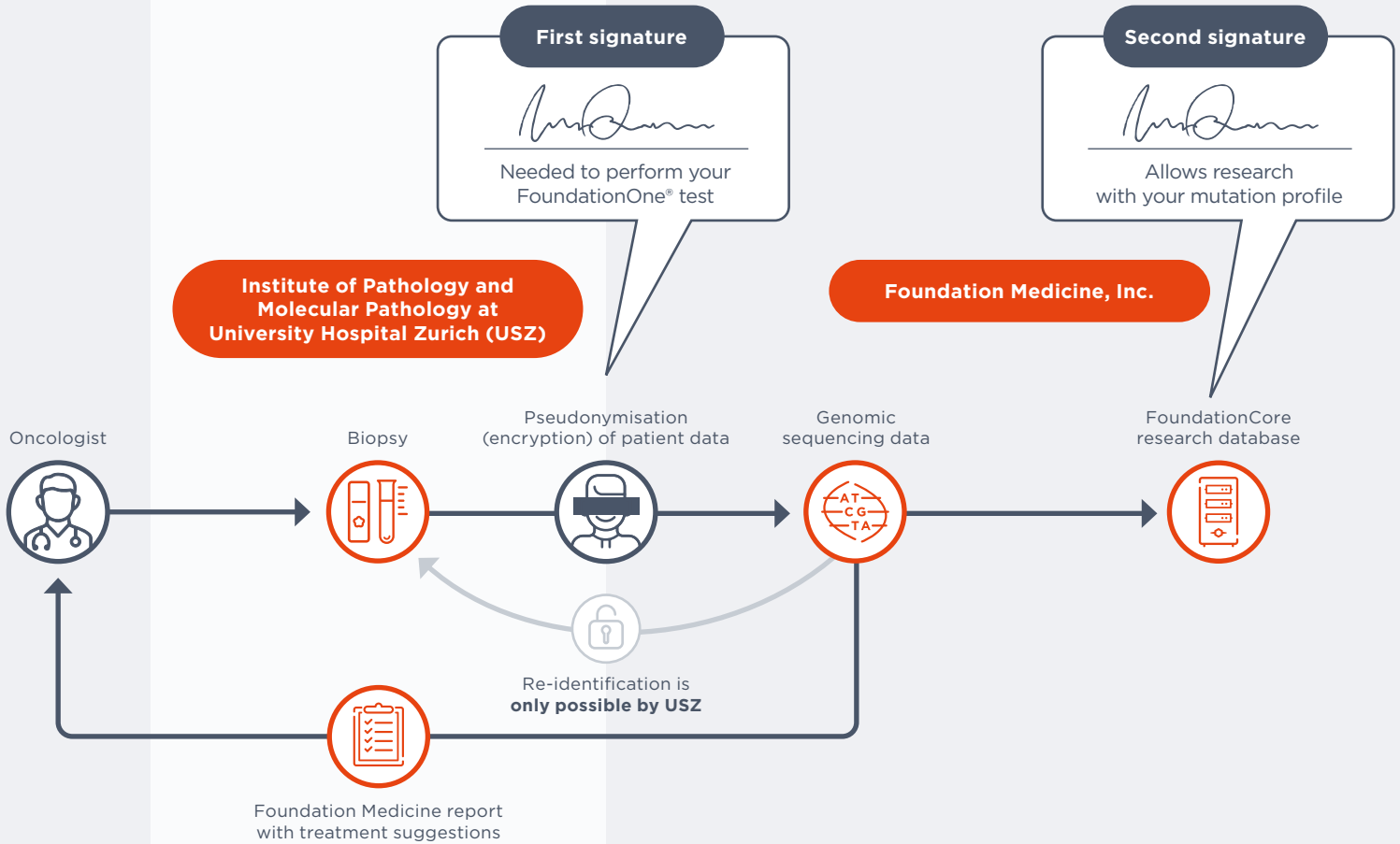


# INFORMATION ON PATIENT CONSENT

This document explains what the two signatures in the patient consent form are for and exactly what happens with your data. Your mutation profile, together with data from thousands of other patients, helps researchers from academic institutions and industry obtain a more complete picture of cancers. This is important for developing new generations of diagnostic tests and cancer drugs.



- Your doctor will send your sample to the Foundation Medicine laboratory at USZ.
- There your sample will be processed and sequenced.
- USZ does not disclose any personal data such as names, addresses or insurance numbers to outside parties. These data always remain within USZ.

- Your pseudonymised sequencing data will be analysed and checked for possible mutations.
- After the analysis, the results are sent to the oncologist in the Foundation Medicine report together with possible treatment options.

- Assuming you have provided your second signature, the analysis result (mutation profile) is saved in the FoundationCore research database.
- This can be used by other institutes for research purposes.

## Example: Personal data



**Hans Muster, Lindenweg 2, 8083 (ZH)**  
 Date of birth: 13 Feb 1965

Diagnosis: lung cancer  
 Sequencing data: AGTGTAGAA...

## Example: Pseudonymised (encrypted) data



**Patient ID 239XE**  
 Date of birth: 13 Feb 1965

Diagnosis: lung cancer  
 Sequencing data: AGTGTAGAA...

### What will happen to your data?

Your genomic data will be recorded by University Hospital Zurich (USZ) and sent in pseudonymised (encrypted) form to Foundation Medicine (USA). Re-identification is only possible by USZ, not by third parties. The data are then analysed using the Foundation Medicine algorithm to find the right treatment options for you. You also have the option of making the result of your genomic analysis available for research by agreeing to have your pseudonymised (encrypted) data included in a research database. Your encrypted data can be processed further to redact or delete all identifiable data, so that they can no longer be traced back to you either directly or indirectly. Data processed in this way are described as “anonymised” and are no longer encrypted.

### How are your data encrypted?

USZ will replace all identifying details – such as your name or insurance number – with a code (laboratory number) before sending your sequencing data to Foundation Medicine (USA). Only USZ can link the analysis data with your personal data through this laboratory number in order to send your oncologist a Foundation Medicine report. The use of your encrypted data and samples and their transfer to researchers in Switzerland and abroad are subject to strict regulations. No directly personally identifiable data will be transmitted outside of USZ. If you give your signed agreement to further use of your data for research purposes, the mutation profile will be stored in the FoundationCore research database in pseudonymised (encrypted) form.

### Why are your two signatures important?

With your **first signature** you allow your doctor to pass on your patient data and tumour tissue to USZ so the test can be performed. You also consent to have your pseudonymised genomic data sent to Foundation Medicine to find possible treatment options for you. We cannot carry out an analysis without this signature.

With the **second signature** you support research into new cancer treatments by allowing the result of your tumour analysis to be included in the FoundationCore database.

### What is the FoundationCore database?<sup>1</sup>

FoundationCore is a research database containing mutation profiles of various tumours from patients. These mutation profiles have been generated with a FoundationOne® test. The advantages are:



Researchers can submit a request for access to the database with a specific research question.



Building knowledge and facilitating research.



Supports the creation of study designs.



Improved understanding of cancer biology.

### What are your rights?

Your consent is voluntary. You have the right to withdraw (revoke) your consent at any time without giving your reasons. For this please contact your doctor or the Laboratory for Molecular Tumour Profiling in the Department of Pathology and Molecular Pathology at USZ. If you withdraw your consent, your data and samples will no longer be made available for research projects. Whether or not you decide to give your consent or if you later withdraw it, this will not affect your medical care in any way.

**If you have more questions, please send them to the following email address: [fmi.pathologie@usz.ch](mailto:fmi.pathologie@usz.ch)**

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1. Foundation Medicine website: <https://www.foundationmedicine.com/service/genomic-data-solutions>; USZ = University Hospital Zurich