An electronic health record accessed with your identity number has been in use in Finland for a long time. Registers requiring an identity number create good conditions for the efficient future utilisation of sample collections from people and the data linked to them. This is a great advantage over many countries.

The sample collections of Auria Biobank, which operates in connection with the Turku University Hospital and the University of Turku, are physically located in hospitals in southwest and west Finland. Samples are collected and combined with the necessary metadata, indicating the clinical information on the sample donor, quantity, date and how the sample has been processed. The samples of Auria Biobank include tissue, blood and DNA isolated from cells.

Providing consent once is enough
The Finnish legislation relating to biobanks is progressive. Consent provided once from the donor of the samples is sufficient for the stored samples to be utilised in various studies and in the future too. The law allows the biobank to contact the sample donors who have given their consent, for example, to enquire about the willingness of the donor to participate in a study not covered by the consent or to donate additional samples.

“In most cases, the contact has to do with drug research. If the patient is interested, they will contact the author of the study directly, and then they will form a separate agreement with the research organisation, after which the matter no
longer involves the biobank”, says Perttu Terho, Vice Director of Auria Biobank.

The Personal Data Act and the Biobank Act are complied with in the transfer of data, safeguarding the privacy and confidentiality of patient information.

Consent for the donation of samples can be given in hospitals or online through an electronic form.

**Sample collection is growing and being digitised**

High-grade prostatic intraepithelial neoplasia in the prostate issue. In addition to tissue samples, Auria collects fresh tissue left over from a diagnostic procedure. The biobank currently collects, for instance, prostate, intestinal, ovarian, pancreatic and liver tissue. Auria Biobank was established by the University of Turku and the hospital districts of Southwest Finland, Satakunta and Vaasa.

New samples are collected from consenting patients in connection with normal diagnostics and treatment. Tissue samples filed in hospitals are scanned, digitised and transferred to databases. Before transfer to the biobank, personal data is removed from the samples and replaced with a code. This ensures the efficient protection of personal data.

Auria collects tissue samples taken in connection with surgery that are left over from a diagnostic procedure, such as cancer tissue, and biobank blood samples taken in connection with laboratory visits.

“After surgery, the tissue sample is taken to a pathologist for examination. Typically, the sample is cast into paraffin and cut into slices with a thickness of a few micrometres which are stained with the colours needed for diagnostic purposes. The pathologist examines the stained tissue sections to establish whether there is a tumour present in the sample, for example. If some of the sample remains, it can be utilised in biobank studies. The sample must not run out, so there should be enough for the hospital to use. Once this has been confirmed, the tissue sample can be used for other research”, says Terho.

Auria Biobank digitises the samples that are needed for research projects.

“The purpose of digitisation is that we can, for example, ask a pathologist to assess the samples and mark the spots where cancerous tissue is found and where there is healthy tissue. The pathologist can do this from anywhere on their own computer, and the samples themselves do not need to be transferred. The digitised images can also be analysed in an automated way using pattern recognition algorithms and methods based on artificial intelligence.”

Auria has previously isolated DNA only from those blood and tissue samples that were needed in projects. Now, DNA isolation is to be done from every blood sample stored.
“Isolating DNA from every sample enhances research. Samples are received and stored, but nothing is yet studied. The samples are left to wait for future research as it is not yet known what the samples may be needed for.”

DNA will be isolated from 16,000 blood samples this year. Going forward, more than 20,000 samples will be taken every year.

The blood sample is taken in conjunction with a normal diagnostic or clinical blood sample.

“We are talking about one extra 10 ml blood sample for the biobank. The blood plasma and white blood cells from the sample are placed in different tubes before being frozen.”

Perttu Terho emphasises that the donated sample is valuable when it can be combined with patient data.

“Researchers may want data on patients with a specific diagnosis, medication and blood count. In this case, it is possible to quickly check the biobank and see whether there are samples that meet these criteria and the associated data exist.”

Biobank material can be used to identify the special characteristics of diseases and drugs. For example, it is possible to learn more about why some patients have side effects from medication and others do not.

“The requests for data and samples are processed by the biobank’s Scientific Steering Committee which convenes once a month.”

“It is important to collect a sensible amount of relevant patient data from as large a number of people as possible. This allows samples from patients who are of interest to research to be obtained for the biobank.”

Sample-related requests from researchers are received every week.

“Based on an analysis, we map the quantity of samples and data in the biobank that the researcher is interested in. If the researcher is satisfied with the outcome of the pre-analysis, they will submit a request for data and samples describing the study and defining the required samples and data.”

The requests for data and samples are processed by the biobank’s Scientific Steering Committee which convenes once a month. The steering committee evaluates the requests. If the steering committee decides in favour of the study, the applicant can proceed to the preparation of a Material Transfer Agreement.

Availability service in the works

In principle, the operations of the biobanks operating in connection with Finnish hospitals are the same. They collect samples from their own hospital districts and store associated data. It would, of course, be a tempting idea to be able to search all the available sample collections in one go. The challenge is that, over the years, the different hospitals have stored and classified
the samples in different ways. Different systems have different information registered, meaning that there is variation in the data provided on patient samples. Data should flow smoothly between the different biobanks.

"Hospital data is difficult to analyse. The expertise of a clinician is required to interpret what has been recorded. The data available is not directly commensurable. It would be important to create an availability service that is able to combine the data of the different biobanks so that at least the basic data would be available."

The Finnish Biobank Cooperative was established in 2017. Its members include hospital districts and universities with faculties of medicine. The purpose of the biobank cooperative is to provide the material in the sample and the data collections of Finnish biobanks to be used by researchers under a one-stop principle. It would provide customers with a unified view and a centralised channel to the materials of Finnish biobanks. The biobank cooperative is responsible for the development of information systems, among other things.

According to Terho, it is possible to combine the associated clinical data relevant to research to the samples. Biobanks will utilise the sensitive data platforms developed by CSC – IT Center for Science when designing the information services of their own.

About 4,000 years ago, a small number of settlers moved to the Finnish territory. The individuals of this new population represented small and narrow genetic material, resulting in the regional enrichment of certain disease genes. This is called a bottleneck phenomenon. The phenomenon is very useful for genetic research. Over-representation of genetic modifications is only observed in populations that have experienced a bottleneck.

Auria Biobank is involved in the establishment of the future genome centre. According to Lila Kallio, Acting Director of Auria Biobank, the way in which the transfer and storage of research and diagnostic sequences will be organised is, so far, only at the consideration stage.

“Genome legislation is being drafted and reform of the Biobank Act is underway. In addition, the new data protection regulation of the EU will also clarify the operations of biobanks.”

According to preliminary plans, the Finnish Genome Center will start its operations in 2019.

Ari Turunen

More Information:

CSC – IT Center for Science
is a non-profit, state-owned company administered by the Ministry of Education and Culture. CSC maintains and develops the state-owned, centralised IT infrastructure.
http://www.csc.fi
https://research.csc.fi/cloud-computing

ELIXIR
builds infrastructure in support of the biological sector. It brings together the leading organisations of 21 European countries and the EMBL European Molecular Biology Laboratory to form a common infrastructure for biological information. CSC – IT Center for Science is the Finnish centre within this infrastructure.
http://www.elixir-finland.org
http://www.elixir-europe.org