

## The String of Pearls Initiative

The String of Pearls Initiative (PSI) is a unique partnership between the eight university medical centres (teaching hospitals) in the Netherlands. First established in 2007 by NFU, the Netherlands Federation of University Medical Centres, the initiative gathers clinical data and biomaterials from all the participating institutions so that together they can promote the advance of science, improve patient treatment and encourage the development of new products. Which in turn strengthens the economic position of the pharmaceutical and biotechnology industries in the Netherlands.

### The pearls

Initially, PSI is focusing upon nine groups of medical conditions, its so-called "pearls". They are cerebrovascular accident (strokes), diabetes mellitus, hereditary colorectal (bowel) cancer, inflammatory bowel disease (Crohn's disease and ulcerative colitis), leukaemia, neurodegenerative diseases such as Alzheimer's, renal failure, rheumatoid arthritis and arthrosis and congenital heart disease. In the future, its activities will be expanded to include other conditions.

### Collecting data and biomaterial

University medical centre (UMC) patients whose conditions fall within one of the "pearls" listed above are asked to allow their clinical data and physical specimens to be included in the PSI database and biobank. What specimens are collected depends upon their nature of their condition, but may include blood, urine, faeces, biopsies and other bodily materials obtained during treatment or surgery. These are collected and stored in accordance with strictly defined procedures. They are kept at the UMCs themselves, in special biobanks – essentially, large freezers in which biological materials, properly classified, can be preserved for long periods of time.

The UMCs also record details of the specimens and clinical data about the patients and their conditions, which are submitted to the central PSI database. The entire

process is governed by strict guidelines, which have been drawn up in line with the applicable standards of medical ethics.

### Privacy and patient consent

Data and biomaterials are collected only from patients who have given their express written consent to do so. A brochure about PSI is available at all the participating UMCs. Together with the information they can obtain from the medical specialists treating them, this enables patients to take an informed decision about whether or not to give their permission.

Protecting the privacy of its donors is an absolute priority for PSI, so a comprehensive set of procedural and technical safeguards are in place. For example, all patient data is "pseudonymised" – that is, stripped of any identifying information. Only in exceptional circumstances and under strict conditions can a person's identity be traced using unique codes associated with their data, and this may only be done through an independent third party for the benefit of the doctor treating them.

### Research using the database and biobank


Compilation of the database and biobank began in 2008, with a view to making the information and physical specimens they hold available for scientific research. Interested researchers have no direct ac-

cess to either facility, but can consult an online catalogue to find out what material has been collected by each "pearl". Data and biomaterials are released for research purposes only after ethical checks have been carried out and the scientific relevance of the proposed study has been assessed. Once an application has been approved, the requested data is retrieved from the central system and made available to the researcher.

### The future

To ensure that all the participating UMCs collect and record clinical data in the same way, the so-called String of Pearls Information Model (PIM) has been developed. This contains standardised instructions for IT specialists at the hospitals, so that they can create suitable data registration applications. It is essential that all information be recorded in the same way in the central PSI infrastructure, as only then can valid comparisons be made between data from different sources and reliable research results generated. Thanks to the use of PIM, it should also be relatively easy to add new "pearls" in the future.

In the meantime, PSI has entered into a number of external partnerships: with PALGA, the national histopathology and cytopathology data network and archive; with LifeLines, a large-scale and long-term population study; and with the Mondriaan Project, an initiative by



the institute TI Pharma. The organisation is also investigating whether it might be possible in the future to forge links with other databases and biobanks, both national and international, in order to generate further opportunities for medical research.

#### **International profile**

Combining the knowledge and skills of eight teaching hospitals has created a

centre of expertise capable of assuming a leading position in Europe. PSI is actively involved in the development of the new European Biobanking and Biomolecular Resources Research Infrastructure (BBMRI) initiative, which aims to enhance the value of biomedical science and so create a more effective research environment for the discipline in Europe. In turn, that will improve the region's competitive position in research

and strengthen European industry on the global stage. Through its participation in BBMRI, PSI intends to propel the Netherlands to the forefront of international biomedical research. PSI is also a member of P3G, the Public Population Project in Genomics, an international consortium established to promote co-operation between scientists investigating the relationship between disease and genetic factors.

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vancement of science, improve patient treatment and encourage the development of new products, as well as strengthening the economic position of biomedical research in the Netherlands. Initially, the project is focusing upon nine groups of medical conditions, its so-called "pearls". In the future, its activities may be expanded to include

others. For more information, you can contact the String of Pearls Initiative at [info@string-of-pearls.org](mailto:info@string-of-pearls.org).