

String of Pearls Institute (PSI)

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Research Areas



Basic Research



Data-Sharing Enabler

At a Glance

- Status: **Active Consortium**
- Year Launched: **2007**
- Initiating Organization: **Netherlands**
- Initiator Type: **Government**
- Location: **Europe**

Abstract

The String of Pearls Institute is a joint project of the eight university medical centers (UMCs, teaching hospitals) in the Netherlands. It concerns a prospective, disease-specific biobank in which anonymous patients' characteristics are documented and followed over a long period. These data are coupled to a biobank containing patients' biomaterials such as intestinal mucosa, feces, deoxyribonucleic acid (DNA), and serum. In case of approved scientific studies — and after approved protocol — additional samples and materials may be harvested.

Mission

The String of Pearls Institute is working on the following syndromes:

Consortium History

In 2005, the String of Pearls Institute was initiated for the group of IBD diseases by the ICC, especially by Daniel Hommes and the other ICC members of that time. Then the project was picked up by the

Netherlands Federation of Universities (NFU), scaled up, and made financially feasible.

Structure & Governance

The String of Pearls Institute work is conducted under the administrative responsibility of the NFU board, which consists of the chairs of the boards of the eight UMCs. The NFU board makes decisions about planning, budgeting, and assumptions. Each member is directly responsible for the activities and communications to UMC shareholders. An executive from the NFU is appointed to the String of Pearl Initiative Executive Board, which is responsible for achieving the objectives.

The String of Pearls Institute was founded with a government grant from the Economic Structure Enhancing Fund (FES). It is the responsibility of the Ministry of Education, Culture and Science (OC&W), which involves the Ministries of Economic Affairs (EZ) and Health, Welfare and Sport (VWS) in the assessment of the project.

Patent Engagement

Research within PSI collects data from patients with particular diseases. Personal identifiers are always removed from patient data, and patients can opt out from participating in research at any time.

Data Sharing

Within the String of Pearls Institute project on multiple diseases (“so-called Pearls”), body materials, and clinical data, including images of patients (donors) in the UMCs, are collected and stored for the benefit of large-scale medical research. To smoothly and carefully manage this process, there are agreements on the collection, processing, storage, and use of the patient data and materials.

Impact/Accomplishment

Publications resulting from PSI research can be found at <http://www.parelsnoer.org/page/Publicaties>

Other website <http://www.icc-ibd.com/parelsnoer-project/en>
Homepage <http://www.parelsnoer.org/>

Points of Contact

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