

The role of the central infrastructure

For the String of Pearls Initiative to achieve its objectives, it needs to gather research data about its nine so-called “pearls” – groups of medical conditions – from the eight participating university medical centres (UMCs). And to do that, a central infrastructure is essential. This is where data from different sources is brought together and made available to authorised researchers who have applied for access to it.

As such, that infrastructure serves as both a technical platform and a management organisation. Its functions are as follows:

- To process, hold and manage the data collected at the UMCs and submitted by them in a secure form;
- To inform researchers and other interested parties about the range of data available to them. This is done through the online catalogue on the String of Pearls website, www.string-of-pearls.org, which provides details of the amount of patient information held in each pearl, together with some key statistics. The data model – including definitions, code tables and other details – can be requested using the catalogue, so that the researcher is able to see in advance what kind of information can be provided;
- To facilitate the release of data collections once the appropriate application and approval procedure has been completed;
- To manage the technical infrastructure and to maintain standards.

The String of Pearls Information Model

The String of Pearls Information Model has been developed in order to classify and manage the more than 1800 different items of patient data collected for the initiative. Its aims are twofold.

- Semantically, to define the data in an unambiguous fashion;
- Syntactically, to define a file format for use by a UMC to submit research data to the central infrastructure.

Within String of Pearls, the model is used to harmonise the interface between local and central infrastructures. Each UMC collects data in its own environment. To ensure that information from these different sources is compatible, agreements have been reached about the definitions used and how the data is submitted to the central infrastructure.

Technical aspects

Bringing together all the data gathered within the central infrastructure should not require highly advanced technology. For this reason, it has been decided to adopt a supplier-independent solution based upon open standards. Key aspects of this are security and support for the information model. An initial version of the central infrastructure became operational in 2008, with improvements and expansions informed by user experience being implemented in 2009 and 2010.

Privacy and security

Since it consists of medical information about actual patients, the research data must be treated with the utmost care at all times. Because of this, security

measures have been incorporated into the system architecture at several levels. To begin with, all the data is pseudonymised. In other words, none of the information released to an authorised researcher can be traced back to a specific patient. A detailed factsheet about the pseudonymisation procedure can be downloaded from the String of Pearls website, www.string-of-pearls.org. Subject to strict conditions, the pseudonymisation protocol does allow for patient identification using data retained by String of Pearls and not made available to researchers.

Various security measures have been implemented to protect communications between the UMCs and String of Pearls, so that only a hospital submitting information can gain access to the central infrastructure.

Researchers have no direct access to the data held. They must apply to the relevant “Pearl” for the release of specific information, as described in the catalogue. If and when such an application is approved, the dataset in question is sent to them.



The String of Pearls Initiative

The String of Pearls Initiative is the result of a unique partnership between the eight Dutch university medical centres (teaching hospitals). Founded in 2007 by NFU, the Dutch Federation of University Medical Centres, the initiative gathers clinical data and biomaterials from all the participating institutions so that together, they can promote the ad-

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.