

A blueprint for all

The String of Pearls Information Model (PIM) is a mainstay of the initiative. For programmers, clinicians and researchers, it serves as a blueprint incorporating all the mandatory definitions used in each “pearl”. As such, it describes down to the smallest detail how data about the various medical conditions covered should be recorded in the information systems and what exactly everything means. This high level of standardisation guarantees consistent registration, so that researchers using String of Pearls data know exactly what has been recorded and how to interpret it.

The first official version of the model (1.2), covering inflammatory bowel disease, was released in October 2008. Further updates appeared over the next few months: version 2.1 in November 2008 also covered hereditary bowel cancer and rheumatoid arthritis and arthritis; version 2.2 in January 2009 included neurodegenerative diseases and cerebrovascular accident; version 2.3 in February 2009 added renal failure, leukaemia and diabetes; and version 2.4 in June 2010 added congenital heart disease.

Unambiguous

PIM ensures that clinicians, researchers and IT personnel all use the same set of agreed definitions. Standardised instructions enable programmers at each of the eight participating university medical centres (UMCs) to create applications that record clinical data related to all nine “pearls” in a consistent fashion. This allows the UMCs to combine their information at a later date and means that the data held in the central String of Pearls computers is uniform. Absolute precision is essential in this respect, since the value of the information for new studies entirely relies upon that consistency: for data from different sources to be shared between them or supplied to researchers, it all has to be recorded in exactly the same way. If users were to receive material based upon different – or not totally unambiguous – definitions, they would first have to harmonise it themselves. Thanks to PIM, all the doctors and researchers involved speak the same language, both literally and

figuratively. This makes it unique in the Dutch healthcare sector, especially given the sheer scale of the project: PIM 2.3 contains no fewer than 2000 distinct definitions, compared with 1400 in version 1.2. To keep the model practicable, those definitions have been grouped into clusters. About half are generic in nature and so have been clustered in such a way that they can be applied broadly throughout both the clinical environment and the world of research. The remainder are linked specifically to the medical aspects of one or other of the nine “pearls”.


New update

PIM has been complete since early 2009, but that does not mean that it has reached its final form. String of Pearls has deliberately opted to develop the model incrementally, meaning that it continues to be built up step by step. This is done in close collaboration with users “on the ground”. Based upon input and feedback channelled through the pearl co-ordinators, the model is constantly being honed and its definitions added to and refined. The next update, version 2.4.0, is due to appear in June 2010 and will expand upon the current model as well as correcting errors in it. Version 3.0, which is scheduled for issue in 2011, will further group and harmonise data fields using the Detailed Clinical Models (DCM) method. In addition, as far as possible it will use the international coding systems defined in Snomed – CT (the Systematised Nomenclature of Medicine – Clinical Terms). This will make PIM even more universally applicable than is already

the case and so broaden its appeal, not just within the participating UMCs but also to other potential users.

National harmonisation

PIM 2.3 is already being used outside String of Pearls – for example, in a partnership between the initiative and PALGA, the national histopathology and cytopathology data network and archive. Another such alliance has been forged with LifeLines, a large-scale and longterm population study in the northern Netherlands. String of Pearls is also participating in the Mondriaan Project, an initiative by the institute TI Pharma to develop a network combining new and established databases in order that the Netherlands can continue to play a leading role in the development of new medicines. As well as including data from institutions taking part in TI Pharma research projects, Mondriaan is also drawing upon patient information from GPs, pharmacists and health insurers. The collaboration between String of Pearls and TI Pharma represents a first step towards the national harmonisation of data exchange in the biomedical sector. This may eventually extend beyond research alone: because doctors at all the Dutch UMCs have agreed upon the definitions it uses, PIM could help to accelerate the introduction of electronic patient records (EPRs) within those hospitals, as well as its own “core EPR”. To ensure that the standards applicable to information technology in the Dutch healthcare sector are consistent across the board, String of Pearls is working closely with Nictiz – the National



IT Institute for Healthcare in the Netherlands – the organisation responsible for developing and harmonising electronic data communications for and about the patient.

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.