VALIDATION PROCEDURE OF THE SYLVIA LAWRY CENTRE FOR MS RESEARCH: METHODOLOGICAL AND PRACTICAL ASPECTS

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Multiple Sclerosis (MS) is the most common neurological disease in young adults. It affects nearly two million people worldwide, including 450,000 Europeans and 400,000 North Americans. The aim of the Sylvia Lawry Centre for Multiple Sclerosis Research (SLCMSR) is to help bringing better treatment options to MS patients earlier. Research work at the Sylvia Lawry Centre is based on a pooled placebo and natural history registry. At present 45 datasets from multi-centre and case-control studies including 20,000 patients are available for analysis.

Since 2002, the SLCMSR has put an institutionalised validation procedure in place that is based on splitting the pooled data into a learning sample and a validation sample. The way it is set up, 40% of the data are available for generating hypotheses, and 60% are held back to eventually confirm fundamental hypotheses independently. In the past years, a large number of researchers have agreed to subject their scientific output to the SLCMSR validation policy. Since then, they have been able to gain practical experience with a split database in different projects.

In this talk, we are going to discuss methodological and practical issues of an independent confirmation of hypotheses, the cost of not using the complete database for the analysis, the increase in validity, and the practicability of our approach for publishing valid results.