Privately owned genetic databases may hinder diagnosis and bar the way to the arrival of personalized medicine

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In response to the on-line publication by the *European Journal of Human Genetics* today (Wednesday) of an article by US researchers led by Dr. Robert Cook-Degan, a former member of the US Office of Technology Assessment, showing that Myriad Genetics, providers of the BRCA1/2 genetic test in the US, has amassed vast quantities of clinical data without sharing it, Professor Martina Cornel, chair of the European Society of Human Genetics' Professional and Public Policy committee, said:

"We are very concerned that such important data is being withheld from those who most need it. Interpreting the variants of unknown significance (VUS) that may be found on analysing the patient's genome plays an essential part in being able to provide proper counselling and if necessary, preventive or therapeutic guidance. By not sharing their data on the VUS obtained from individuals undergoing BRCA1/2 testing, where Myriad is the sole commercial provider of a test in the US, geneticists have been unable to develop the up-to-date algorithms that are necessary to best interpret the effects of genetic variants. While Myriad has access to public databases in order to help interpret their VUS results, this is currently not reciprocal.

"We know that, regrettably, medical geographic inequities are common, but what is particularly worrying about this situation is that it is the first time that such inequities have been based on a lack of access to clinical

information, rather than lack of a product. Myriad's stated aim to enter the European market more vigorously may lead to unfair competition with academic institutions for predictive precision. It is vital that progress towards personalised medicine, which holds out so much promise, is not hindered by companies maintaining private genomic databases. Policymakers should take an urgent look at the regulatory and reimbursement issues involved in genomic testing in order for all the data that is essential to understanding the clinical significance of VUS to be made public, to the benefit of patients and healthcare providers alike."

Provided by European Society of Human Genetics