



The
Medical
Research
Council

Biomedical Informatics Research Division

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April 20, 2009

Dr Robert Shafer
Stanford University
Palo Alto, CA
USA

Dear Dr Shafer

Letter of Support for HIV Drug Resistance Database

I am sorry to hear of the unfortunate threat that has arisen to the Stanford HIV Drug Resistance Database (HIVDB) and would like to offer you my support in lobbying to have the decision to restrict access reconsidered.

As we enter a period in which antiretroviral treatment will be scaled up in Africa it is essential we maintain public access to resources such as HIVDB to help limit the spread of drug resistant quasi-species. I believe it will be disastrous to have important information required to effectively treat patients locked up in a proprietary database application that is unaffordable to the vast majority of treatment programs in developing countries. This would be tantamount to denying Africans access to information to help patients failing antiretroviral therapy and compromise the vast investment the world is making in HIV treatment. I have personal experience of situations in Africa where data has been locked up in database applications because the cost has become unaffordable as the number of patients on the system increases and the licensing costs scale proportionally. There is even anecdotal evidence of applications preventing archiving dead patients so they remain payable, probably as part of some denominator in a public health statistic.

As Principle Investigator of a large HIV Drug Resistance project in South Africa we have standardized on HIVDB for genome interpretation in the treatment failure clinics we are developing. We are critically dependent on the data and algorithms in HIVDB and our projects will be severely compromised if this resource is not available to us. We have also started the Southern African Treatment and Resistance Network that follows the HIVDB model and makes sequence data from Southern Africa openly and freely available to researchers and clinicians. In my personal view, the present issue goes beyond a simple patent infringement and cuts to the very core of the debate regarding the patenting of scientific observational data. I thought this practice had largely been debunked in the human genome project and flies in the face of recent trends to improve access to important scientific information as a public and research good.

It seems inconceivable that US law would uphold a patent proclaiming to cover every possible method for generating advisory information from patient data. If at all, the present patent could surely only cover the inventor's own narrow method? What if one were to use support vector machines or neural networks or a combination of expert rules and machine learning? Surely this would be excluded from the patent. I am sure your knowledge existed before the patent as prior art and therefore is excluded? Stanford itself has a long and illustrious history of groundbreaking research in biomedical data representation and medical decision-making that certainly predates this patent.

Hopefully reason will prevail and the decision-makers will not give in to these spurious claims.

Kind Regards

A handwritten signature in blue ink, appearing to read 'Chris Seebregts'.

Chris Seebregts, PhD
SENIOR TECHNOLOGY MANAGER
PRINCIPLE INVESTIGATOR: FREE STATE HIV DRUG RESISTANCE PROJECT