

Suggested Projects: White House Innovation Fellows
5 - Global Blue Button for Rarer Diseases and 350+ Million Beneficiaries:
Extending www.grdr.info

I [suggest] an exciting, high-impact, related project - a rapid learning international Blue Button health system that, in six months, will start to provide vital benefits to the 350 million+ patients, in the US [including veterans and their families] and worldwide, who suffer from the 7,000+ rarer diseases and conditions (defined as <200,000 cases in the US). These rarer conditions do not provide the economic incentive for new drug development and they are often treated in many different, limited ways by off-label use of drugs for other conditions and without much hope for breakthroughs. But 5%-7% of the world's population (350 million+) are affected and an online electronic health record (EHR) patient registry solution will work: 1.) Immediate analysis will discover who is getting better results; 2.) the costs to organize clinical trials will drop steeply; 3.) Patients and physicians, via new Apps, will receive immediate notification of discoveries.

NIH's new <http://www.grdr.info> registry system can support 7,000+ rapid learning global networks. A team can organize several strategies - e.g., pop-up boxes on Google, activated by diagnostic or billing codes or disease names with options for US and international patients to obtain and transmit health records with privacy guarantees. Patients and physicians in all countries will benefit: the State Department can help to open doors with the EU, UK, China, and India who are moving to EHR systems.

Lloyd S, Etheredge
June 5, 2012