Date: Mon, 18 Jan 2010 15:34:04 -0500
To: "Dr. Baruch Fischhoff - Chair, National Academy of Sciences Study on Social
& Behavioral Science and Improving Intelligence for National Security" <baruch@cmu.edu>
From: Lloyd Etheredge <lloyd.etheredge@policyscience.net>

Subject: Progress: Global rapid learning networks for international health

Dear Dr. Fischhoff and Colleagues:

I just wanted to bring to your attention the exciting news of new leadership from the Obama Administration to build global rapid learning systems in international health, with new databanks and analysis tools.

The progress is along the lines outlined in my early memoranda [# 4 on www.policyscience.net] about political opportunity analysis and the earlier DNI Report about new opportunities for US leadership. NIH is moving quickly to build these networks for all "orphan/rarer" diseases (less than N=200,000 diagnosed patients in the US) that are underfunded and under-researched and for which patient registries, electronic health records, and online linkups can codify experience and bring quick, new benefits to about 25 million Americans and hundreds of millions of people in all countries.

The underwriting of 19 rapid learning consortia ($ 117 million) is described on http://rarediseases.info.nih.gov. A series of conferences and seminars on building the patient registries and biorepositories got underway last week, headed by Steve Groft and Yaffa Rubinstein. Kaiser has agreed, with a visionary grant from the Robert Wood Johnson Foundation, to contribute full patient and genomic data from its 8 million patients for rapid growth of public domain, research capabilities that will be available online to users in all countries.

These initiatives accompany earlier, larger, projects underway re women's health and breast cancer; a new initiative for linkups, electronic health records, and rapid learning + international cooperation in cancer research will be announced in the near future. Core investments that can be used for rapid (public domain) international learning/databanks and analysis tools are under development for Medi-

care and Medicaid population, with EHR funding from the Obama Administration.

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