Date: Mon, 07 Aug 2006 10:25:21 -0400
To: "Dr. Guy de The - Co-Chair, IAMP" <dethe@pasteur.fr>, "Dr. Anthony Mbewu - Co-Chair, Interacademy Medical Panel" <anthony.mbewu@mrc.ac.za>
From: Lloyd Etheredge <lloyd.etheredge@yale.edu>
Subject: IAMP & the first (US) national Rapid Learning System (for healthcare)
Cc: "Dr. Laurence Ehlers - Federation of European Academies of Medicine" <laurence.ehlers@cfwb.be>, "Ms. Muthoni Fanin - IAMP Secretariat" <iamp@twas.org>, "Dr. Ji-Sheng Han - Chinese Academy of Sciences":hanjisheng@bjmu.edu.cn, hanjisheng2005@gmail.com;, "Dr. Peter Lackmann - Academy of Medical Sciences UK":PJL1000@cam.ac.uk, m.manning@acmedsci.ac.uk;, "Dr. Jan Lindsten - Royal Swedish Academy of Sciences":jan.lindsten@cmm.ki.se, rsas@kva.se, karin@kva.se;, "Dr. Gunnar Oquist - Royal Swedish Academy of Sciences":gunnar.oquist@kva.se, diskh@kva.se;, "Dr. Dimitry Orlov - Russian Academy of Medical Sciences":orlov@ramn.ru, lumel2006@yandex.ru, "Dr. Nancy Pritchard - Australian Academy of Science" <nancy.pritchard@science.org.au>, "Dr. Kiyoshi Kurokawa - Science Council of Japan" <kurokawa@is.icc.u-tokai.ac.jp>, "Dr. Yumei WEN - Chinese Academy of Engineering":ymwen@shmu.edu.cn, lxj@cae.cn, kjc@cae.cn;, "Dr. Bob Williamson - Australian Academy of Science" <r.williamson@unimelb.edu.au>,

Dear Dr. de The and Dr. Mbewu:

The vision (discussed in the following announcement) for national rapid learning, which could become international, might be of interest to the InterAcademy Medical Panel and to institutions and individuals in your network.

with my best regards,

Lloyd Etheredge

Good news! Our first national rapid learning system (for healthcare) has started to get underway.

I'm forwarding a summary (1, below) of the design issues and implementation steps identified at the stakeholders conference in Washington. Harvey Fineberg, the new President of the Institute of Medicine, is taking the lead. Additional information and the original papers are available online at www.iom.edu/ebm. As the IOM summary notes, many national institutions are lagging and have not yet adapted to the pace which new technology makes possible.

Background

We now have 17+ million electronic health records, in standard formats in large databases (US); and also many existing and new drugs and treatments whose efficacy and side-effects can be evaluated more quickly, and which can be targeted to patients as new genome data for each patient becomes available and these data systems can be developed and collated/mined by academic and private sector researchers. [Several of the large private HMOs (e.g., Kaiser) also include social and behavioral data for selected populations to assist learning & patient feedback/empowerment about disease risk, onset, management, and treatment efficacy.] And we are just at the beginning . . .

- The vision also works internationally. It may be easier to develop in other countries with national healthcare systems that can make centralized decisions about electronic health records and large N databases w/ privacy safeguards. Identical formats across all countries are not necessary if the emerging systems are designed at the basic level to include all relevant data & allow fast and accurate translations across formats for online datamining.

Additional Developments: RWJ

You also might be interested in the grant announcement (2, below) from the Robert Wood Johnson Foundation for the development of Personal Health Information Manager software - a personal electronic health record that can (voluntarily) interface with the new US national rapid learning system. The winning designs probably will allow add-in modules for individuals with different health needs, etc. One of the background ideas is to give away the first 50 million copies to create a critical mass quickly and an open-architecture platform/market that the nonprofit and for-profit sectors can build upon. (Open architecture systems can be adapted by clinics & research projects in UDCs.) The vision also works internationally.

Building on the Healthcare Prototype?

Exciting times! This healthcare prototype also raises the question of whether there may be other policy areas where new, rapid learning (national/international) systems are possible.

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Additional information (Item 1)

Dear Colleagues:

I am forwarding a summary of key issues identified at the recent Institute of Medicine Roundtable to develop a national (US) rapid learning healthcare system. A printed volume will not be published until next year, but the agenda book and speaker presentations are now available online at: www.iom.edu/ebm.

As we begin to think about an international rapid learning system for healthcare, identical formats across all countries are not necessary if data systems include all relevant data & allow easy translations across formats. The Index Medicus /National Library of Medicine (US) has done pioneering work on nomenclature issues.

Lloyd Etheredge

On the behalf of the IOM Roundtable on Evidence-Based Medicine, we would like to thank you for your participation in our workshop on *The Learning Healthcare System,* and to share with you an initial summary of some of the key issues and themes that emerged during workshop proceedings. Because these will help shape the foci of particular interest in the work of the Roundtable and the IOM, we would appreciate having your perspective as a participant about the key issues raised, and their priority. We would also like to take this opportunity to solicit any feedback you may have on the workshop content or conduct. Depending on the initial responses, we may develop a follow-up query instrument to solicit suggestions on priorities and strategies, but in the meantime, please send any feedback or comments directly via email to lolsen@nas.edu.

The workshop covered a wide range of topics and issues but several common themes and issues were identified by participants, including the importance of:

Adapting to the pace. The need for continuous learning and a much more dynamic approach to evidence development and application□one that takes full advantage of developing information technology□given the rate at which new interventions are developed, as well as new insights about individual variation in response to those interventions.

Culture change: The need for culture change to enable the evolution of the learning environment as a common cause of patients, providers and researchers

New clinical research paradigm: The development of a new clinical research paradigm□one that draws clinical research more closely to the experience of clinical practice, including the development of new study methodologies adapted to the practice environment, and a better sense of when RCTs are most practical and desirable.

Electronic health records: The essential application of electronic health records as a prerequisite for long-term change, if properly defined, utilized and broadly deployed.

Clinical data as a public utility: The need to see the collection of data and development of evidence as a public good, including re-assessing both issues related to ownership and to interpretations of HIPAA and other patient privacy issues that currently slow progress toward a system that constantly improves clinical insights.

Data base linkage and use: The potential for structured, large databases as new sources for evidence, including issues in fostering interoperable platforms and in the development of new means of ongoing searching of those data bases for patterns and clinical insights.

Incentives: The need to develop incentives to draw research and practice closer together, develop the needed patient records and interoperable platforms to foster more rapid learning.

Public engagement: The need for improved communication about the nature of evidence and its development, and the active roles for patients and healthcare professionals in evidence development, and dissemination.

Scientific broker: The potential utility of a credible scientific broker□to foster the shift in clinical research paradigm, the consistent and complementary use of standards of evidence, the development of consistent recommendations and to help

identify priority issues for systematic assessment.

Leadership: The need for leadership on these issues to marshal the vision, nurture the strategy, and motivate the actions necessary to create a learning healthcare system.

Agenda book materials and speaker presentations are available at: www.iom.edu/ebm. A summary of the workshop will also be available soon and a compilation of manuscripts elaborating on participant presentations will be published and available through the National Academies Press by early 2007. Thank you again, and we look forward to your continued involvement in Roundtable sponsored activities.

Sincerely,
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Additional Information (Item 2)
New RWJF Program Promotes Design of Innovative Personal Health Record Systems

The Robert Wood Johnson Foundation (RWJF) is pleased to announce **Project HealthDesign: Rethinking the Power and Potential of Personal Health Records**, a new $3.5 million national program to stimulate innovations in personal health information technology. Project HealthDesign encourages health and technology pioneers to imagine a next generation of personal health record (PHR) systems that would empower patients to better manage their health and health care.

Project HealthDesign supports the development of interoperable personal health record systems that will provide a range of flexible tools that can best support individuals' needs and preferences. Specifically, it will support up to 10 teams of technology designers – working closely with consumers – to design and test prototypes of innovative PHR applications that can be built upon a common technology platform. By enlisting the expertise and creativity of designers, patients, health professionals and informaticians to design PHR systems, the program aims to greatly expand the ways that PHRs can support patients' specific needs and medical providers' ability to provide optimal care.

RWJF is pleased to collaborate with the California HealthCare Foundation, which provided $600,000 in additional funding for *Project HealthDesign*.

The Call for Proposals (CFP), issued today, invites applicants to create consumer-focused personal health applications and test prototypes with target populations. The CFP is available at www.rwjf.org/cfp/projecthealthdesign.

Project HealthDesign will host Web Conference Calls on July 27 (2 PM EDT) and August 2 (1 PM EDT) – participation in these calls is strongly encouraged. They will provide prospective applicants the opportunity to learn more about the program and this grant competition and participate in a real-time Q&A session with RWJF and *Project HealthDesign* staff. To register for the calls, please visit www.projecthealthdesign.org.

The application deadline is Tuesday, September 19, 2006, at 2:00 PM EDT.

We encourage you to share this announcement with interested colleagues and/or to include a notice of this new program and funding opportunity on your Web site, and in relevant journals, newsletters, listservs or other publications. For additional information on *Project HealthDesign* and this funding opportunity, please visit www.projecthealthdesign.org.

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