DRAFT

Six Steps to a National Rapid Learning System for Medicaid

by

Lloyd S. Etheredge [1]

NIH's emerging National Collaboratory Network (with 20-30 million, Everything Included, electronic health records) and its Precision Medicine Report suggest a new, six step strategy to accelerate rapid learning for Medicaid and its high-need populations.[2]

We know that the health of many Medicaid patients is adversely affected by the societal problems and conditions that America tried to solve in the Great Society programs (e.g., low income, poor education, chronic mental illness, broken homes, adverse circumstances affecting child development, alcohol and drug abuse). Today, it is possible that, by gleaning and refining measures from several decades of social science and public health research, the added data in the National Collaboratory Network can reveal new, complex pathways and switch mechanisms

---

[1] Director, Government Learning and International Scientific Networks Projects, Policy Sciences Center, Inc., a public foundation. Contact: lloyd.etheredge@policyscience.net and (301)-365-5241. I am indebted to Lynn Etheredge for discussion of these ideas. Comments welcome.

[2] "The HCS Research Collaboratory represents a paradigm shift in clinical research" - Dr. Francis Collins, NIH Director, quoted in the NIH Press Release of September 25, 2012, http://www.nih.gov/news/health/sep2012/nccam-25.htm. For the evolving strategic framework see http://commonfund.nih.gov/hcscollaboratory/ and Susan Desmond-Hellmann and Charles L. Sawyers (co-Chairs), Toward Precision Medicine: Building a Knowledge Network for Biomedical Research and a New Taxonomy of Disease (Washington, DC: National Academies Press, 2011). The wider vision also is presented in Francis Collins, "A Vision for a National Patient-Centered Research Network." Presentation to the National Workshop to Advance the Use of Electronic Data in Patient-Centered Outcomes Research. July 2, 2012, online at http://www.pcori.org/assets/2-Collins-Slides-Network.pdf

affecting health problems in Medicaid populations. These discoveries may, as they have for cancer, bring us to reconceptualize traditional diagnoses and discover that disabling and expensive medical conditions covered by the Medicaid program can be affected at multiple points (including early detection and prevention in biologically vulnerable populations) with personalized, precise, medical treatment.[3] In turn, because Medicaid spending is about one sixth of total US health spending and it is concentrated among a small number of high need Medicaid enrollees, these creative discoveries may be a highly effective and rational strategy to reduce federal and state health expenditures.[4] [In 2008, these so-called "dual eligibles" were 15% of the Medicaid population but, nationally, 39% of Medicaid spending.[5]]

This project envisions six strategic planning workshops (with 12-15 leaders and experts each) to design the architecture for a national rapid learning system for Medicaid patients. The first three Startup Planning workshops will address priorities for adding sociological and society-linkage data and rapid analysis. The focus of the startup architecture will be to support leading State Medicaid systems that want to create electronic health records for R&D and precision medicine in the context of the larger (eventually, 20-30 million patients) National Collaboratory

---

[3] Concerning cancer discoveries see the articles about applications of the new framework by Gina Kolata in the New York Times in the summer and fall of 2012. For example, "Genetic Aberrations Seen as Path to Stop Colon Cancer," July 12, 2012; "Study Divides Breast Cancer into Four Distinct Types," September 23, 2012; "Study Points to Tighter Pairing of Drugs and Patients," September 9, 2012. Online.

[4] Facts about the Medicaid program are available online at the Kaiser Foundation's Website, www.kff.org/medicaid/

[5] Gretchen Jacobson, Tricia Newman, and Anthony Darnico, "Medicare's Role for Dual Eligible Beneficiaries," Kaiser Family Foundation Issue Brief (April 2012), online at www.kff.org.

DRAFT

Network.[6] [7]

[Code is the common law of the Internet and the new world of Big Data. It will be infinitely easier (now, at the beginning) to identify the public health research and social science variables, a core set of measures, and designate software codes. The alternative - waiting until a large portion of the Collaboratory network is populated by physiological measures alone and then going back to add Medicaid-relevant data that should have been included in the first place - could waste many years. The leading State programs who participate in this element of R&D and precision medicine design will have a strong case to secure initial co-funding from the NIH Collaboratory and (since the individual data investments can produce cost savings and improved care) from Medicaid itself.]

---

[6] The N of augmented dual-eligible and other Medicaid R&D records that the NIH National Collaboratory system wishes to underwrite can be discussed with NIH planning groups. Startup States will be determined by sponsoring organizations for the project. Selection probably will depend upon their willingness to provide leadership for the entire package of securing the benefits of new R&D and precision medicine.

For example: 1.) Massachusetts already has decided to convert State Medicaid records to electronic form. 2.) California is a natural leader, with strong university expertise in public policy and social problems, in biomedical research and the analysis of Big Data. 3.) Maryland has the advantage of NIH, FDA, and the I-270 corridor, the leadership of Kaiser in the Washington Metropolitan area, and substantial Medicaid demands arising from unsolved societal problems in Baltimore. However there may be a wider universe of interested candidates: a core group of states are involved with the Center for Health Care Strategies (www.chsc.org) and rapid learning for Adults with Complex and Special Needs; seventeen states have been building leadership capacity and have participating in the Medicaid Leadership Institute (www.medicaidleaders.org) since 2009.

[7] These leading State Medicaid systems might expect priority for federal assistance to build their systems. Medicaid might, rationally, invest in the $1,000/patient genomic and other data as a way to reduce its long-term national costs and improve healthcare for its patients.

DRAFT

I. <u>Startup Projects</u>

The first three steps will glean, and begin to populate the new R&D system with, the best measures from several decades of public health and social science research that should be part of a State's Medicaid patient component in the N=20-30 million patient R&D system. Because of economic and health impacts, an initial focus will be the nine million low-income Medicare beneficiaries (discussed above) who also receive Medicaid. These populations are sicker and frailer than typical elderly populations; they also are disproportionately affected by severe and chronic mental illness and one or more other health conditions.

<u>Procedures</u>. The format for the six workshops will be similar: 1.) An initial planning group organized by the sponsoring organizations will identify 12-15 participants/experts for a Working Group to address the question; 2.) A professional researcher/consultant will meet with each participant/expert to discuss their recommendations and issues for Working Group discussion. The researcher/consultant will draft a 25-30 page discussion paper summarizing these meetings and identifying issues for a Working Group discussion; 3.) A 1½ day conference of the Working Group will discuss the issues and scope-out any further organizing and strategic steps;[8] 4.) The researcher/consultant will revise the initial paper, which will be forwarded with any dissenting views to the sponsoring organizations.

A. <u>Step 1: Select the Best Measures of Sociological and Individual-level (Societal Linkage) Variables</u>

The health impacts of major sociological variables have been studied across several decades and the Great Society years also developed and applied a wide range of social science theories to

---

[8] The working group may recommend a larger conference or a set of initial measures and a process for further research and possible revision in the light of learning. It also will consider creative ideas and new measures for rapid testing.

explain how society affects health-related behaviors.[9] [10] Now, for the future of biomedical research, the first strategic planning project needs to select and prioritize variables and assess different definitions and different measurement methods that show social linkages and candidate pathways for brain and physiological effects.

A key finding from this history is that the sociological-level variables are not, in themselves, determinative: human beings can be remarkably resilient. [For example: Werner and Smith followed about 700 high-risk children from birth to adulthood and found that "most kids make it" - however, for unexplained reasons, "one out of six of the adult subjects was struggling with a syndrome of "chronic financial problems, domestic conflict, violence, substance abuse, serious mental health problems and/or low self-esteem."] [11] One scientific challenge (in the spirit of the Precision Medicine Report) is to create added R&D data systems that can help to disclose the unique switch mechanisms and treatable pathways for physical and mental health in lives that seem to go off-track. (Cognitive, emotional, motivational, social-relational and other systems

---

[9] See Donald A. Barr, Health Disparities in the United States: Social Class, Race, Ethnicity and Health (Baltimore, MD: Johns Hopkins University Press, 2008) and the Annual Reviews of Public Health series (online at www.annualreviews.org/journal/pubhealth) notably in vol. 33 (2012), Sara Bleich et al., "Health Inequalities: Trends, Progress, and Policy," pp. 7-40; Ana Diez Roux, "Conceptual Approaches to the Study of Health Disparities," pp. 41-58; and in vol. 32 (2011), Paula Braveman et al., "The Social Determinants of Health: Coming of Age," pp. 381-398, *loc. cit.* and in (2010), the Symposium on Public Health Significance of Genomics and Eco-Genomics, pp. 1-103.

[10] An overview of thirty behavioral science theories (e.g., cognitive psychology, social learning theory, etc.) developed and applied to social problems in the Great Society years is Lloyd S. Etheredge, The Case of the Unreturned Cafeteria Trays (Washington, DC: American Political Science Association, 1976), online at www.policyscience.ws.

[11] E. Werner and R. Smith, Journeys from Childhood to Midlife: Risk, Resiliency, and Recovery (New York: Cornell University Press, 2001), p. 37; see also Bonnie Bernard, Resilience: What We Have Learned San Francisco: West Ed, 2004), p. 7 et passim.

seem to be jointly inhibited, perhaps by common suppressive effects in brain mechanisms and endocrine and other pathways.) In America, for these challenges, the health records and patients are uniquely concentrated in the Medicaid system.

Here are a dozen examples of Medicaid-specific design issues:

- 1.) <u>The importance of a status gradient is well-established</u>. What are the active elements of socio-economic status that should be measured and included in Medicaid records? [12]

- 2.) <u>What genetic measures of race or ethnicity</u> should be added to self-reports in current Medicaid records?

- 3.) <u>Beyond religious affiliation, what measures of religiosity and social involvement</u>? In this area (and in others) there have been important discoveries and refinements over the decades. [Earlier self-report measures of church attendance showed almost half of Americans attending church on a weekly basis while a new and more accurate (time budget) interview method shows

---

[12] For a recent review and introduction to the literature: Christopher McLeod et al., "How Society Shapes the Health Gradient: Work-Related Health Inequalities in a Comparative Perspective," in <u>Annual Review of Public Health</u> (2012), *ibid*., pp. 59-73. Also Michael Marmot, <u>The Status Syndrome: How Social Standing Affects Our Health and Longevity</u> (NY: Holt, 2005). The status effects are documented in the UK where there is universal access to national healthcare.

On the history of these measurement issues see the earlier review by Penny Liberatos et al., "The Measurement of Social Class in Epidemiology," <u>Epideomiologic Reviews</u>, 1988, 10:1, pp.. 87-121 and N. Krieger et al., "Measuring Social Class in U.S. Public Health Research: Concepts, Methodologies, and Guidelines," <u>Annual Review of Public Health</u>, 18 (1997), pp. 341-378.

DRAFT

26%.][13]

    - 4.) <u>What social-psychological attitudes should be measured and included</u> (e.g., self-esteem, locus of control, optimism)?

There also are creative, higher-order hypotheses about linkages that are explicit in the published literatures or that can be gleaned across a range of studies. For example:

    - 5.) <u>Stress and social isolation</u>. What society-linkage and physiological measures of stress, social isolation, and related pathways should be included? [14]

    - 6.) <u>Inhibitions of autonomy and limited abilities for abstraction</u> - e.g., for planning, or cognitive reframing, or subjective distancing - occur repeatedly as important intervening variables that limit resilience and recovery.[15] This suggests that a personality trait/cognitive processing style discovered by Witkin *et al.*, with a genetic base and such effects on brain functions, (called "field dependence/independence") might be at work. A standard measure (the embedded figures

---

[13] Philip S. Brenner, "Identity Importance and the Overreporting of Religious Service Attendance: Multiple Imputation of Religious Attendance Using American Time Use Study and the General Social Survey," <u>Journal for the Scientific Study of Religion</u>, 50, (June, 2012), pp. 103-115. Americans (by self report) over report their church attendance but Western Europeans, by contrast, do not.

[14] See, for example, Andrew Steptoe and Mika Kivimaki, "Stress and Cardiovascular Disease: An Update on Current Knowledge," <u>Annual Review of Public Health</u> (forthcoming, 2013), *loc. cit.*, "Our updated meta-analyses of prospective studies published until 2011 show a 1.5 fold . . . increased risk of coronary heart disease among adults experiencing social isolation and a 1.4-fold . . . excess risk for workplace stress with adverse metabolic changes being one of the plausible mechanisms."

[15] E.g., Werner and Smith, *op. cit.*; Benard, *op. cit.*

DRAFT

test) may help to nail a common causal pathway in vulnerable populations.[16]

    - 7.) <u>Is Home Health Care Preferable</u>? In the same spirit: It is possible to interpret the resilience literature as implying that activating and sustaining the brain mechanisms associated with autonomy, control of one's life, purposive planning (etc.) will (by still-mysterious switches, links, and processes) be healthy? Thus, this package of social linkage measures might be selected with special care, because it could have direct policy implications (see the discussion, below, for community planning and rapid learning in Step 4).

    - 8.) "<u>Marginal Status</u>." Can an index of this higher-level sociological diagnosis be created? It may be helpful to capture a cumulative lifetime history of adverse experiences: traumatic and isolating events in childhood, failures to graduate from high school and to acquire a marketable skill, alcohol and drug abuse and arrests and prison time that begin early, a history of unemployment with a series of low-paying jobs, betrayal by a spouse and marital breakups, living alone. What should be coded, where?

    - 9.) <u>Hierarchical, identity-defining, (benevolent) psychodramas</u>. Resilience-increasing relationships with a caring, older adult may activate protective brain pathways that are similar to the observed effects (in strong, positive religious identities) of being loved by all-powerful Deity (i.e., who loves and respects the individual, will see them through troubles, and has a plan for

---

    [16] See Benard, Op. cit., pp. 17-35 and 119-130, *passim*. For a discussion of Witkins work: Maria Kozhevnikov, "Cognitive Styles in the Context of Modern Psychology: Toward an Integrated Framework of Cognitive Style," <u>Psychological Bulletin</u>, 133: 3 (2007), pp. 464-481.

    Early research suggests that field dependent cognitive processes may increase susceptibility to psychopathology. I am not aware of studies investigating whether training to develop field independent brain processing capacities is possible and beneficial.

their lives). The shared brain mechanism may be a strong hierarchical psychodrama, sustained in the imagination and memory via the visual cortex, that produces a sustained brain and physiological effect that is protective against the slings and arrows, and adversities, of a secular and/or current reality.[17] How can these brain mechanisms and pathways be measured?

- 10.) A Primate Subordination Syndrome may activate, across species, a primitive mechanism of cognitive and motivational inhibitions, endocrine and other changes, stress effects, and adverse health effects. This mechanism may be present in low status human populations as an unrecognized and common contributor to a range of societal and life problems whose causes also are mysterious to the individuals involved. How can a societal linkage with these hierarchical psychodramas and these syndrome effects be measured?[18]

- 11. Dependency in a welfare system. A shared, politically-charged diagnosis in America is that a *dependency syndrome*, in which people refuse to take responsibility for their own lives and

---

[17] Religious identities may affect individuals by several pathways, including the social capital and support that they provide and other cultural benefits. On the multiple importance of religion, the sociologist David Mechanic remarked (personal conversation): "All of the kids in my neighborhood were poor. The difference was that the Jewish kids knew they were going to college."

Emerging ideas for a hierarchical psychodrama paradigm to explain and explore emotional effects, non-rational behavior, and imagination/visual cortex links are discussed briefly in Lloyd S. Etheredge, "Wisdom in Public Policy" in Robert Sternberg and Jennifer Jordan (Eds.,) A Handbook of Wisdom: Psychological Perspectives (NY: Oxford University Press, 2005), pp. 297-328, pp. 312-314 and in a series of working papers, online at www.policyscience.net.

[18] E.g., Robert Sapolsky, "The Influence of Social Hierarchy on Primate Health," Science, 308, April 29, 2005, pp. 648-652. Note Sapolsky's argument that "[I]ncreasing evidence suggests that the [health] gradient arises from psychosocial factors. Subjective SES can be at least as predictive as objective SES," p. 652. Sapolsky's interpretation is that being poor in social systems with high inequality also activates interpretations and brain mechanisms with physiological impact.

to act with autonomy and purpose, produces an unhealthy future for society and for the individuals involved. The syndrome also is alleged to be caused by the excessive and misguided benevolence of a welfare state and to affect (in a recent estimate by a Republican Presidential candidate) 47% of Americans. This recurring hypothesis may be wrong, but it is unlikely to go away and it should be evaluated. It is possible that Republican beliefs are a speculative misinterpretation of behavior that results from failed educational systems, or the effects of lower status via a Primate Subordination Syndrome, or the cumulative effects of stress, or a disempowering operating style of welfare bureaucracies, or the effects of other mechanisms that the Medicaid rapid learning system will discover.

- 12.) Diet (and other health-related behaviors that may be affected by culture and social class). For a subset of Information Donors who are willing to provide diet information: What data should be collected?[19]

B. Step 2: Identify, Upgrade and Add Data from Other, High-Priority Sources

A second strategic project to build a national rapid learning system for Medicaid is to identify the other specialized data systems that can be augmented and added to the National Collaboratory for the benefit of Medicaid patients. For example:

1.) Longitudinal research databases of child and adolescent development - and many other ongoing longitudinal studies that may have clues about Medicaid areas of responsibility - have

---

[19] See Walter Willett and Meir Stampfer, "Current Evidence on Healthy Eating," Annual Review of Public Health (forthcoming, 2013), online at http://www.annualreviews.org/doi/abs/10.1146/annurev-publhealth-031811-124646.

DRAFT

evolved in the US and abroad.[20] Their organizers might be willing to begin including electronic health records and related information, in standard code formats, in their databases.

2.) <u>Lifelong medical providers and mental illness</u>. A likely partner would be the VA system, with medical records beginning in youth, at the time of military service. The VA (as a lifetime health provider) shares responsibilities with Medicaid for the prevention and successful treatment of chronic and severe mental illness. It also has the ability - perhaps a unique ability that Medicaid cannot develop - to add data that evaluate counseling and psychotherapy and the national network of imaging facilities to study the brain-linked processes that (by unknown mechanisms) contribute to future health.[21]

3.) <u>Aging research is a potential breakthrough strategy for the precision medicine paradigm and Medicaid rapid learning</u>. If the aging process increases susceptibility to many health problems (including mental and physical problems that require institutional care via Medicaid), and this transition can be observed before it begins and can be measured (e.g., by the length of telomeres) then "aging" becomes an explicit, measurable, co-morbidity diagnosis.[22] Bold discoveries and personalized treatments for the aging process itself may steeply and quickly improve health in many patients and markedly lower Medicaid costs.

---

[20] See, for example, Deniz Erten-Lyons, et. al., "Review of Selected Databases of Longitudinal Aging Studies," <u>Alzheimer's and Dementia: The Journal of the Alzheimer's Association</u>, 8:6 (November, 2012), pp. 584-589.

[21] See also Thomas Insel, "Improving Diagnosis Through Precision Medicine," NIMH Director's Blog, November 15, 2011, which describes fresh thinking that is underway. Online at http://www.nimh.nih.gov/about/director/2011/improving-diagnosis-through-precision-medicine.shtml

[22] See also Lyons et al. *op cit*.

DRAFT

All major lifetime health providers (including HMOs and VA) might be willing to contribute augmented EHR data to the National Collaboratory to nail-down all of the pathways.

4.) <u>Augmented databases to explore why standard treatment protocols are less effective for Dual-Eligible Medicaid Patients</u>. There are a range of research-oriented organizations (Kaiser, in the HMO world, the VA) that treat patients across a wide demographic range and with standard treatment protocols. An exciting observation via Kaiser (personal communication) is that Medicaid dual-eligible populations, when they are treated by standard protocols for health problems, do less well. Can this discovery be confirmed? If so, this phenomenon, which also may be true of (low) status gradient populations, suggests that there may be undiscovered, common pathways that are activated in the most challenging Medicaid patients. The new NIH Collaboratory system offers the possibility of fast statistical comparisons and breakthrough comparative analyses to discover these additional switches and pathways, affecting Medicaid patients, which may be independently treatable.

C. <u>Step 3: Upgrade to Cloud Data Analysis and Enroll Researchers for Rapid Learning</u>

Rapid learning also requires rapid data analysis and support for the creative process. Thus, plans to populate large R&D datasets to benefit Medicaid-specific responsibilities need to co-evolve with strategic plan for fast data analysis.

The economics of Cloud computing is changing. Today, the costs of electrons and terabytes of storage are less than the cost of the time of senior researchers to review grant proposals for the competitive use of (once-scarce) resources. Locating datasets and analysis tools in the Cloud, for free desktop use for initial discovery and education, 24 x 7, allows a wider universe of science-trained people to test hypotheses relevant to Medicaid patients, and at the speed of thought

DRAFT

rather than the speed of the NIH grant process.

Some of the most exciting and rapid learning may be generated by physicians themselves who can routinely log on, use the genetic information and other data of a Medicaid patient that they are treating, and investigate diagnostic and treatment possibilities (using their own research skills and an online statistical analysis package with a good user interface). Very soon - perhaps within two years? - every Medicaid doctor in the core of leading Medicaid states may quickly be able to get a "best fit" selection of medications from a patient's genetic and other profile data rather than the current guesswork and trial-and-error processes of selecting among possible drugs and dosage levels.

- A good plan for the economical use of resources might be for Medicaid's advisers to develop smaller (N=2,000 to N=10,000) curated Reference Datasets for initial discovery and education. [Further Reference Datasets can be drawn, or other uses of the 20-30 million patient R&D system can be approved, by an application with acceptable scientific justifications.] Planning for educational uses also will support long-term R&D: The national strategic plan should facilitate rapid training of researchers, graduate students, undergraduates, and even smart high school students in these new, exciting, Big Data and *in silico* methods. A professional staff, with online teaching materials, can educate users about the special characteristics of each dataset, the most frequent errors made by beginners, etc. Experiments to support the creative process also may be possible: a Medicaid Reference Dataset for Alzheimer's Disease (also specifically designed for educational use) could train, and begin to enroll, tens of thousands of science students and new investigators, worldwide.

II. <u>Acceleration</u>

The next set of three strategic planning workshops will address issues of accelerating the

13

DRAFT

learning rates and practical benefits for Medicaid patients:

D.) Step 4: Prototype Community-Based Rapid-Learning for Precision Medicine

The "falling through the cracks" problem has been recognized as a key issue for State Medicaid leadership and healthcare delivery. Medicaid patients often share the requirement that other (accountable) human beings and health/government organizations must assist them. The health services, and many other services required by these populations, are provided by a multiplicity of different physicians, hospitals, and government agencies in any community.[23] *De facto*, for Medicaid patients, the health care they receive can (and perhaps should be) coded by a package of community-specific variables, not just their medical prescription. What new codes in new electronic health records for Medicaid patients can help communities to share data and discover and deliver the best, personalized health care?

I do not have a full agenda to suggest, but here are three examples:[24]

1.) An ER-Net with Biometric ID. A typical Emergency Room visit of a high-use, dual-eligible, Medicaid patient may present a complex, special needs case of an individual who cannot communicate effectively and reliably about a medical history or medications, who may be scared and crazy or on drugs (or seem to be), who may have several things wrong, who may be unconscious and otherwise unable to give their name. Thus, it would be very helpful for all State

---

[23] There is a learning project by State Medicaid programs in Maine, Massachusetts, Minnesota, New Jersey, Oregon, Texas, and Vermont to improve community learning and performance: See the Center for Health Care Strategies, "Advancing Medicaid Accountable Care Organizations: A Learning Collaborative," July, 2012, online at www.chcs.org.

[24] We are beginning to develop national data systems of organizational Best Practices and checklists: www.apqc.org (for example) may have suggestions for Working Group 4.

DRAFT

Medicaid agencies, as they shift to electronic health records, to establish a privacy-assured Emergency Room network with immediate access to a patient's basic medical history and diagnoses, medications, and contact information for personal physicians and social workers/responsible adults. The State Medicaid systems could be built with a capacity for fast biometric ID (heel print, retina scan, finger print, etc.).[25] It may be possible to add a recording so that a trusted voice can deliver a reassuring message. And other personal information, included with a patient's knowledge and consent, might be included online.

2.) "Where is the Breakdown?" Diagnostic Codes. When patients seem to fall between the cracks, local community health providers could assist national rapid learning by developing standard diagnostic codes, based on thoughtful knowledge of each patient. For example, it is possible that drugs for serious mental illness produce side effects. "Stopped Taking Medication" may be a frequent diagnosis of why a mentally ill patient is found wandering the streets and is brought to the Emergency Room by police. If there is a further diagnostic entry "Unwanted Side Effects Mentioned by Patient" this could trigger a larger R&D process to compare the full genetic and other National Collaboratory data of these patients and discover a better, personalized treatment by an equivalent drug that does not produce these unwanted side effects. (To get to this lesson, we need to have the diagnostic/software codes "Stopped Taking Medication" and "Unwanted Side Effects").

3.) Is Home Health Care Preferable? What Institutional Designs are Healthier and Why? As discussed above (the planning process of Step 1) studies of social linkage variables and resilience can be interpreted to suggest that activating brain mechanisms associated with

---

[25] The system also could send an immediate alert to physicians, social workers, and other contact individuals listed in the electronic health record.

autonomy, abstract thinking, personal control, and purposive future-oriented thinking will (by unknown mechanisms) have a positive effect on health. This suggests the testable proposition that allocating resources for some kinds of packages of home health care and community services [the best designs for which will need to be researched] may actually be healthier than institutional care.[26] And (once characteristics are properly coded in the R&D databases) that some kinds of institutions will be seen to have social-psychological characteristics and practices that are healthier - by demonstrable physical pathways - because these mechanisms remain activated. It may be, in the era of personalized medicine, that Medicaid physicians will explicitly prescribe (and Medicaid will pay for, because it is healthy and cost effective?) sunlit rooms and options for patients to have, and care for, living plants. If it is healthier for patients to have small pets, and a physician agrees, are these benefits sufficient that this option should be honored by institutions? Medicaid institutions can be ranked (and perhaps improved) by a wider set of these measures and criteria.

E.) Step 5: Enroll International Rapid Learning for Medicaid High-Need Cases

The second acceleration workshop (Step 5) will identify strategies for international data partnerships that expand, to the fullest extent, the range of relevant R&D variations in the NIH Collaboratory Network. The Kaiser-NIH-UCSF-RWJ Foundation pilot project (http://www.rpgeh.kaiser.org) intentionally oversampled sub-populations in California with Asian/Pacific Rim genetic ancestries (e.g., India, China, Japan) as a basis for such international collaboration and discoveries of genetic x environmental interactions, influences of culture and new diets, etc. This dimension should be activated to accelerate potential discoveries.

More broadly, the goal of Step 5 is to evolve and implement the best strategy for divisions of

---

[26] Although perhaps, someday, a small pill can substitute if necessary.

labor and large-scale collaboration. China has four times the US population and commitments to develop electronic health records and to global leadership in pharmaceuticals. It has, in a sense, four times the rational interest of the US Medicaid program to address health issues of aging populations - for example, Alzheimer's disease and its own "dual-eligible" populations. [27] [28]

   - With growing awareness of the NIH Collaboratory/precision medicine vision, worldwide demand for rapid learning and the benefits of precision medicine are likely to grow. We might anticipate that patients, healthcare professionals, the pharmaceutical industries, and national health systems in most countries will be open to developing and sharing electronic health records (with genomic and other data) if they also can, with reciprocity, learn quickly of discoveries keyed to these biomarkers and build their own systems for personalized, precision medicine. [29] [30]

---

[27] Concerning Chinese national plans for electronic health records as a foundation for reducing costs and improving effectiveness, see research supported by the US Trade and Development Agency: Ken Zita, "China Healthcare IT," Journal of Emerging Knowledge on Emerging Markets, 1:1 (November, 2009), online at http://digitalcommons.kennesaw.edu/jekem/vol1/iss1/6/

[28] The Beijing Genomics Institute (http://www.genomics.cn/en/index) has ambitious programs, including a million micro-ecosystem genomics project which could be very helpful if the human biome is implicated in the health-disease pathways. BGI is intended to support the develop of new pharmaceuticals and it could be open to collaborative investigations of Alzheimers and "dual eligible" conditions as part of its investment in a one million human genomes project. They have several offices in America and would be easy to invite to a Step 5 working group. See also, concerning the human biome, http://commonfund.nih.gov/hmp/.

[29] Another reason to move quickly with these investments is that there may be spectacular growth potential in these areas that can contribute to a sustained economic recovery. As compatible codes are established across all of the world's major healthcare systems any software developer has the economic incentives of serving a global market.

[30] See also Bartha Knoppers et al., "Sampling Populations of Humans Across the World: ELSI Issues," Annual Review of Genomics and Human Genetics, 13, 2012, pp. 395-413, Online at www.annualreviews.org.

DRAFT

- Strategic globalization and data sharing, designed with sensitivity and foresight, also may capture new insights. Traditional Chinese medicine, for example, has its own remedies, theories of body-mind relationships, and of energy flows in the body: codes that allow for dual (Western and traditional) encoding of diagnoses and treatments may open a new universe of investigations and discovery. Buddhist medical practices also include a refined pharmacopeia of meditation techniques (that deserve their own software codes).

F.) **Step 6: Design a Fast Nationwide Roll-out for Medicaid Patients and Personalized Medicine**.

Medicaid's rapid learning system will begin (Steps 1-3) with full, social-linkage supplemented, data contributed from several leading States.[31] However the full benefits from the National Collaboratory System, with 20-30 million patient records and full genomic, epigenomic, societal linkage, etc. data, will require upgrades, and shifts to electronic health records, by all remaining State Medicaid systems. (This is true because at least a portion of each individual genome may need to be sequenced to do precision medicine.) Contingency planning needs to begin so that, as discoveries start to come through the Medicaid-included NIH R&D system, the rest of the national Medicaid system is upgrading to secure precision medicine and the best quality care (daily) to all Medicaid patients. There also needs to be a reliable national rapid notification system so that all high-need Medicaid patients or their accountable health providers receive relevant information quickly. Email notifications can be keyed to genetic and diagnostic and other codes rather than wait for a physician to discover a link in a published article.

---

[31] It is not clear how many State Medicaid systems and dual-eligible patient records (augmented with sociological and social-linkage data) the NIH Collaboratory will need for fast discovery and how soon the national shift to personalized, precision medicine for Medicaid patients should (because of anticipated usable discoveries) begin. These are design issues for discussions between Medicaid and the NIH Collaboratory planners.

DRAFT

When he presented NIH's vision and new research paradigm last summer Dr. Francis Collins used an Olympics reference: "Go for the Gold!" [32]

November 2, 2012

---

[32] Francis Collins, "A Vision . . . ", *op. cit.*