PERSONALIZED HEALTH MANIFESTO

An old-fashioned call to arms and action plan for a new age of health care

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Director, The Center for Life Science Policy, UC Berkeley

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Director, The Center for Life Science Policy, UC Berkeley

This document was prepared with the participation of thirty-five life science leaders representing science, medicine, business, government, patients, law, and the media (a complete list of participants appears at the end).

American society is on the cusp of a vital new era of health care, one in which medicine will shift from primarily addressing illness to a greater emphasis on prediction and prevention, and on individualized care. This historic transformation comes from a deepening understanding of biology, the emergence of new technologies, and a rising demand by individuals to understand and take charge of their own health. Yet a widening gap exists in integrating and implementing this promising new epoch of personalized health.

Resistance comes from traditions and attitudes that emerged during an age when medicine was limited primarily to diagnosing and treating disease, and by the prevailing use of drugs and protocols targeted more for populations and averages than for individuals. Even today, the biomedical enterprise overwhelmingly focuses on developing and paying for costly drugs, procedures, and devices that will be deployed after a person gets sick, with too little consideration for their personal physiology and circumstances.

This dominance is now being challenged. Discoveries in genomics, proteomics, environmental toxicology, microbiology, biocomputing, and many other fields are poised to provide unheard of insight into a person's future health risks, and also to offer individualized options for improving health and wellness, and for managing disease.

Significant impediments and gaps remain, however, in applying this "new science"—not only in the clinic, but also in funding, infrastructure, regulation, law, business, education, and communication. Some of these gaps are unavoidable and naturally occur with any new discovery, while others are avoidable and potentially fixable.

A major hurdle is the unintended consequence of a system that has devoted considerable time and resources on basic research and on creating an ever more specialized phalanx of experts delving into the mechanisms of life. Over the years, this reductionist enterprise has produced critical insights that have made an age of personalized health possible. But it also has encouraged a parsing of

knowledge and a silo effect that has made it difficult to capitalize on vast new stores of knowledge about human biology.

The time has come for an intensive focus on integration, the crucial complement to reductionism. Basic research and specialization remains crucial to the biomedical enterprise, but a reordering of priorities is required to stress the application and translation of what has been learned to improve health and to reduce health care costs.

Integration requires, first, a new urgency for scientists to work together to focus on the whole human organism; and, second, for society to absorb and implement scientific discoveries in the realms of clinical medicine, law, government, education, and commerce with greater creativity and resolve. To realize this vision will require coordination, funding, and a mandate for bold action.

To launch a new era of personalized health does not require a radical new blueprint for change. Rather, it can utilize an existing body of suggested proposals, reforms, and plans already put forth by individuals and organizations inside and outside of government. Some of these ideas have been tentatively initiated, but they require significantly more funding and support.

In order to accelerate a transformation to personalized health, we, the undersigned, call on the life science community, policymakers, patients, and society to take the following actions:

First, to acknowledge that:

- New scientific discoveries are enabling a shift from a paradigm of health care based on illness to one equally centered on prediction, prevention, and personalized health.
- A balance between specialization and integration needs to be restored, with an emphasis on the whole human organism as much as its parts, and as much on individual patients as populations.
- Gaps exist that exacerbate the normal lag between discovery and application, both inside and outside the scientific community.
- Shifting to a health care system based as much on healthy wellness as illness is achievable, and can be accelerated by systematic planning and proper funding.

Second, to advocate the following:

- A Personalized Health Project that will:
  - Recruit key leaders from science, medicine, business, policy, government, patient advocacy, ethics, law, and the media;

- Study and assess specific “gaps” between innovation and application, and assign task forces to address each substantial gap;
- Create a blueprint for implementing specific initiatives and enhancing existing projects in the public and private sectors to support predictive and preventive health care; and,
- Target, prioritize, and develop funding streams for the validation and application of new discoveries based on integrating individual discoveries and projects into a holistic model based on the needs of individuals and populations.

Third, to offer support for reforms in:

Education

- Establish a new academic discipline focusing on the science of integration, including educational programs, funding, and journals.
- Modify medical education and scientific training to emphasize wellness and predictive and preventive medicine, and a deeper understanding of the links between the new science and the clinic.
- Provide incentives for medical trainees to pursue primary care and integrative fields such as medical genetics.
- Organize an awareness campaign on the need to integrate fields within the life sciences and between the life sciences and society.

Policy

- Refocus regulation and oversight to better utilize science and technology to streamline the drug and diagnostic approval process.
- Embrace a new model based on predictive and preventive medicine, and personalized treatments.
- Develop standard data elements for this new and emerging field.
- Remove barriers to the flow of scientific information by adopting open source models for publishing studies and organizing databases.
- Support improvements in information technology to better integrate data and to develop effective predictive models for populations and individuals.
- Create methods and programs to assess the true cost-benefit of personalized health science and protocols.

Patient Participation

- Encourage and enable the rise of the patient-consumer in health care.
- Arm people with validated information on predictive and preventive tests and protocols, and on lifestyle options such as nutrition, diet, and exercise.

Business

- Encourage entrepreneurs, investors, and commercial efforts to develop new products and protocols based on the science of personalized health.
- Create a Human Integration Fund: a hybrid of public and private money dedicated to investing not in individual efforts, but in groupings of efforts that jointly target a disease or system, or the human body.

Reimbursement

- Establish a reimbursement process that pays for and encourages predictive tests, prevention, healthy wellness, and targeted treatments.

Ethics and Global Health

- Study the impact and the ethics of personalized health initiatives to ensure their adoption is safe and effective, and that privacy, personal choice, and access are protected.
- Work to develop predictive and preventive strategies that are suitable for both the developed and developing world, and work to develop funding and initiatives for global personalized health.

End of Life

- Acknowledge that illness and death remain a part of life, and continue a dedicated focus on personalized medicine to better customize treatment options, and encourage the use of palliative care where indicated.

Shifting to a health care paradigm that embraces healthy wellness and personalized health is a formidable challenge that will take many years. Yet we believe that this transformation can be accelerated with a thoughtful and comprehensive plan to advance the science and practice of personalized health, and that no time is better than now to launch this effort.

Expert Panel:

The following individuals participated in the development of the Personalized Health Manifesto and have endorsed it; neither they nor anyone else has had any editorial influence over this document.

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