

# Health Reform: The Time Is Now

## Principles for comprehensive reform

(These consensus principles resulted from a meeting convened by multiple stakeholders. They were then vetted by more than 100 coalitions, organizations and companies. Finally, they were disseminated widely and XX entities signed on in support of these principles. See “Methodology” on page 4.)

It is imperative that we engage in health reform, not just healthcare reform. In order for this transformation to be comprehensive, actionable, and sustainable, it must look at health as a continuum. Five main areas serve as the pillars of an effective health system: access, economics, delivery systems, patient empowerment, and the research to care continuum (see Figure 1).

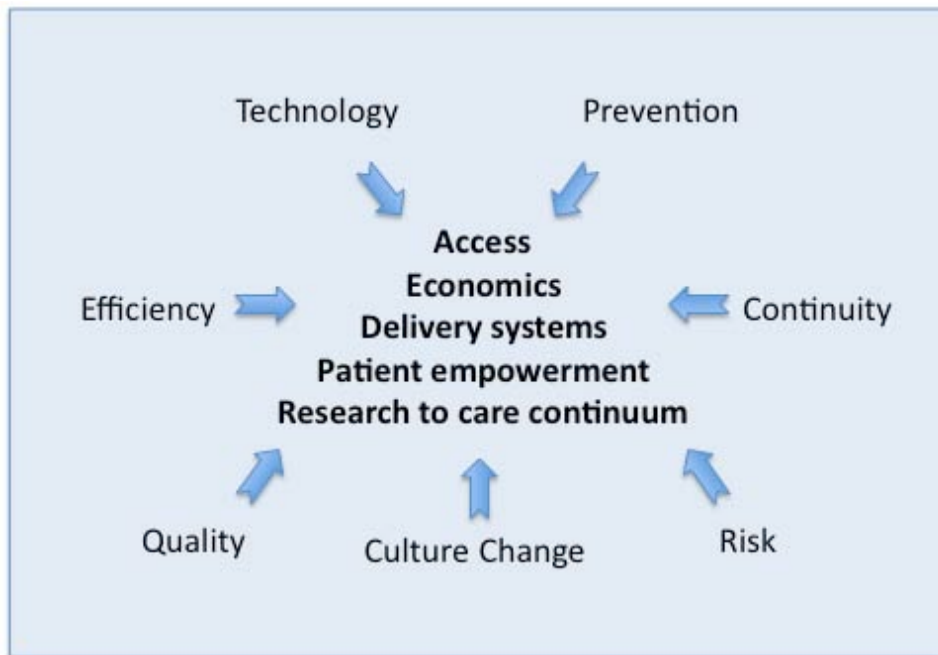


Figure 1

### Cross-cutting principles:

A number of core principles emerge from these five areas. It is critical to remember that these areas, just as the fields that impact them, cannot function independently. They must be connected to create the change we seek.

- Ultimately, each of us is responsible for the health system, and in it, our own health.
- The health system must be consumer/patient-centered.
- Education and empowerment of individuals, families, communities and their healthcare providers is critical, particularly in underserved communities.
- Creation of standards, and coordination of systems and stakeholders is key.

- We must achieve a balance of proactive and reactive care throughout the lifespan.
- Emphasis of care should focus on quality of life as defined by the patient and medical benefit, not only extension of life.
- Opportunity for innovation must be incorporated into each facet of the health system.

**Access:**

*Create universal access to optimal care that provides an established benefit to individuals, families and communities.*

Access must be viewed from multiple angles—including (but not limited to) language, location, culture, type of disease, literacy, complexity of decision-making, and finances—all of which contribute to the provision of optimal care. Optimal is defined as appropriate, efficient, and timely care based upon personal and familial medical history and genetic information. Care should include prevention, diagnosis, and treatments that balance quality of life and medical benefit. We must not only give access, but also help individuals understand their access.

To achieve optimal care, we must:

- Create a flexible system of evidence-based medicine that allows for innovation in the evidentiary standards that define benefit;
- Ensure that all individuals have a role in their clinical decision-making;
- Make credible, culturally appropriate, information freely available to patients and providers on evidence around treatments, treatment options, support, resources, and options for delivery of services;
- Help patients and providers use this information to make informed decisions about appropriate care, course of treatment, and health decision-making;
- Provide tools and resources to help all stakeholders navigate the medical system and understand health information with the goal of creating an intuitive system that eliminates the need for such tools;
- Ensure health literacy is an integral part of the educational system.

**Economics:**

*Realign financial incentives to center on the health of people.*

The health system must carefully consider economic rewards and penalties. These financial incentives provide more than just direct motivation for patients and providers, but also mirror what we view as the priorities for the system. As such, financial incentives should be fundamentally realigned to support prevention, and focus on the highest quality care for individuals, families and communities. Coordination, innovation, and coverage should all be thought of in terms of the health of the individual. Costs and profits must be viewed from within this framework.

To put patients first, we must:

- Establish a clear minimum standard for coverage and care;
- Educate patients and their caregivers on efficiently navigating the health system;
- Enhance investment at the point when individuals enter the medical system to balance with end of life care;
- Incentivize healthcare providers' time with the patient;
- Incentivize coordination of systems and fields;
- Fuel and reward innovation in research and healthcare to encourage further investment.

### **Delivery Systems:**

*Coordinate delivery across all spectrums of care.*

Individuals are desperately in need of support systems that are interconnected and accessible. Health must be understood across the spectrum, focusing on wellness and not on sickness. From prevention to acute care, and from primary care to specialty care, existing systems must be coordinated. Not only will coordination allow better flow of information and lower costs, but it will also provide much needed accountability.

To coordinate care, we must:

- Resolve provider workforce issues with energy and creativity.
- Provide education that encourages accountability among providers and patients;
- Create a feedback loop to assess the effectiveness of both financial and behavioral incentives to improve delivery systems;
- Create standards for health information to be safely shared between providers and patients and among providers;
- Use health information technology to improve access to information and balance privacy and confidentiality of data.

### **Patient Empowerment:**

*Create an individual sense of ownership and responsibility for health and wellness.*

The healthcare system continues to move further away from the concept of individual ownership and responsibility. A reformed health system must center on the individual and as an active participant in his/her healthcare. This can be achieved through access to information, novel use of technologies, and a healthcare system that incentivizes proactive individuals in the context of their family and/or community.

To empower patients, we must:

- Integrate health education at every life stage and every stage of medical care;

- Encourage a team-based approach to healthcare with valued provider-patient time;
- Incentivize wellness and individuals' proactive engagement in his/her own health;
- Take advantage of new technologies, personalized medicine, and family history to concretely connect an individual to his/her own health;
- Educate the general public about the value of clinical trials in an effort to improve engagement, recruitment, and retention efforts;
- Provide individuals with access and clear understanding of their medical records.

### **Research to Care Continuum:**

*Link the research and healthcare systems and increase research focus on quality of life and health outcomes.*

A long-term investment in research is integral to a successful health system. Investment in research will ultimately save dollars and stimulate the economy. In addition, concrete benefits in quality of life and standards of care are accrued. It is important for the research enterprise to be more closely aligned with health and healthcare both in terms of more targeted development of treatments and better application of existing services.

To focus research, we must:

- Implement and integrate comparative effectiveness research and personalized medicine together;
- Increase research on wellness and prevention and disseminate key clinical trial results, positive and negative;
- Implement health information technology solutions to create a feedback loop from research to care and care to research;
- Develop guidelines for public-private partnerships regarding proprietary information sharing, privacy, confidentiality, and incentives;
- Create a clinical trial system that is accessible to potential participants, including access to compassionate use;
- Develop evidentiary standards for clinical research.

We have an unprecedented opportunity to shape the health system of this nation. Working together, and not in competition with one another, we can achieve great things. Ultimately, our health is up to each one of us, and we need a health system to support us.

### **Methodology:**

Over the past few months, Genetic Alliance held a series of Salons across the country. In these meetings, individuals from every stakeholder group came together, leaving their special interests and intellectual property at the door, to explore health in open space. In this information age, with the tools of social networking and a need to accelerate

basic science's translation to treatments and services, Salons offer an opportunity to vision, strategize, disrupt and take effective steps toward a collaborative system. This "emergency meeting" on health reform emerged from these Salons.

On June 17, 2009 from 12- 4pm EDT, individuals in the health community came together for an urgent meeting on healthcare reform. This meeting was convened in an open partnership between health organizations, including the Biotechnology Industry Organization, the Coalition for Affordable Health Coverage, the Coalition for 21st Century Medicine, FasterCures, Genetic Alliance, Inspire, and Research!America. Individuals participated in the event through many avenues, including: attending the meeting in Washington, DC, Twittering, and blogging in real time. The principles and recommendations articulated here were created by a process of understanding that specific causes and issues are examples of more fundamental ideas. Health reform will require sacrifice but intelligent analysis of issues and resources will result in effective and transformative change. The many stories and faces upon which these principles are based can be found at:  
<http://informhealthreform.blogspot.com/>

## **Signatories:**

The following organizations have signed on to these principles.

AA CSA Foundation  
Alliance for Aging Research  
Alpha-1 Association  
Alpha-1 Foundation  
Alström Syndrome International  
American Self-Help Group Clearinghouse  
American Sleep Apnea Association  
Angioma Alliance  
ARPKD/CHF Alliance  
Associação X Frágil do Brasil  
Association of Gastrointestinal Motility Disorders, Inc.  
Autism Society of America  
Brazilian Genetic Alliance  
BVVL International  
CareTALK, LLC  
Coalition for 21st Century Medicine  
Coalition for Heritable Disorders in Connective Tissue  
Cutaneous Lymphoma Foundation  
Detroit Medical Reserve Corps  
Dystrophic Epidermolysis Bullosa Research Association  
Ehlers Danlos National Foundation  
Family Voices

FasterCures  
Genetic Alliance  
Hereditary Angioedema Association  
Hereditary Disease Circle  
HHT Foundation International  
HumanGeneticsDisorders.Com  
In Need Of Diagnosis, Inc.  
Inspire  
Kids With Heart National Association for Children's Heart Disorders, Inc  
Long Island Breast Cancer Action Coalition  
Lymphatic Research Foundation  
MHE Research Foundation  
Myelin Project  
National Eczema Association  
National Foundation for Ectodermal Dysplasias  
National Gaucher Foundation  
National Marfan Foundation  
National Tay-Sachs & Allied Diseases Association, Inc. (NTSAD)  
Nature Genetics  
Northern Nevada Genetic Counseling  
Pachyonychia Congenita Project  
Pacientes de SIDA pro Politica Sana  
Parent Project Muscular Dystrophy  
Progeria Research Foundation  
Prostate Cancer International  
Pull-thru Network, Inc.  
PXE International  
Research Advocacy Network  
Rett Syndrome Research Trust  
Southwestern Oklahoma State University  
Technic Solutions, LLC  
United Mitochondrial Disease Foundation