The Roadmap for Personalized Health Care
Presented by The Forum on Personalized Health Care

The Roadmap for Personalized Health Care (PHC Roadmap), launched at the 2010 National Summit on Personalized Health Care, is designed to be an actionable primary roadmap for the development and deployment of precision, personalized health care. The living online Roadmap document will be a catalyzing force in orchestrating a transformation of health care from its current reactive, inefficient state into far more effective and affordable systems and approaches.

The Opportunity—and the Imperative
We are on the brink of a watershed era in health care—but we also stand on the razor’s edge of a precipice. Will it be a time of breakthrough or of breakdown? The answer to this question depends in great measure on whether we embrace the promise of transformative technologies by supporting their development and deployment, and equipping them with compelling business models—which will in turn undergird the establishment and maturation of mutually-reinforcing value networks.

The barriers to the health care of the future are real—and daunting: recalcitrant incumbents cloaked in Byzantine legislation and stultifying regulation; promising technology drivers stuck in neutral with little visible hope of procuring the funding that will fuel their development and power meaningful innovation in health care delivery; and systemic “grand mal seizures” fueled by myopia of approach from participants throughout the health care landscape.

Our current health care landscape is made up of heterogeneous, largely disparate entities and communities. Health care IT, health care information exchanges, molecular medicine, Health 2.0, mHealth, personalized health care, medical home and other communities shine their respective spotlights on specific problems or industry needs, many of them essential. Yet there is no common focal language or point of departure to knit together, harness and focus the exchange of ideas and efforts among these groups. The PHC Roadmap is uniquely positioned to fulfill this crucial orchestration role.

The Solution: The Roadmap on Personalized Health Care
The promise of a new health care that is proactive and responsive rather than reactive and inflexible is both real and attainable. Yet to repeal and replace today’s reactive and unresponsive health care with precision, individualized care will require the greatest efforts of the most forward-thinking leaders in industry, government, education and health care delivery, acting decisively and in unison.
They will need a compelling, reliable Roadmap to light their way forward—an industry-wide orchestrated effort that tackles the problem by fostering enabling technologies, innovative business models, sustaining value networks and facilitating social/societal infrastructures.

The Roadmap for Personalized Healthcare represents such an industry-facilitated orchestration. Driven by pioneering, courageous and visionary stakeholders committed to a personalized transformation of healthcare, the primary goals of The Roadmap include:

1. Accelerate the emergence of disruptive innovations in health care by developing and curating a broad, multi-stakeholder approach that addresses all four primary elements of disruption.
2. Provide coordination and orchestration of stakeholder efforts at the scientific/technical level, the commercial/industry ecosystem level, and the societal/social level.
3. Create an ongoing forum that allows ongoing interaction and iteration on the “playbooks” for these efforts, based on new opportunities and emerging technologies.
4. Attract the support of key influencers from the private and public sectors, including elected officials and regulators, to develop enlightened, informed and coordinated new legislative and regulatory approaches.
5. Highlight personalized/precision medicine best practices/approaches, and encourage their dissemination—including pilot projects that help “nail” best practices before “scaling” them.
6. Conduct vigorous educational outreach/media relations campaigns that engage consumers, including patient advocacy groups, in a broad discussion of transformative health care that carries the discussion to the heart of the societal mainstream.

The Roadmap will empower stakeholders in PHC and the larger health care community—including patients, researchers, vendors, doctors, payers, investors, and community and government leaders—with a tangible artifact that can guide and influence the movement’s efforts in a coordinated manner to maximize returns on effort, encourage the pooling of resources, and eliminate zero-sum competition for attention and influence.

Led by Dr. Clayton Christensen and Kimball Thomson under the direction of the board of directors of The Forum on Personalized Health Care, the Roadmap will draw from and build upon Dr. Christensen’s analysis of how disruptive forces can be put to work to help effect systemic change in diagnosis and patient care. It will also draw sustenance from the analysis and hands-on experience of PricewaterhouseCoopers, Leavitt Partners and other key industry collaborators.
Unleashing the Power of Disruptive Innovation in Health Care

Clayton Christensen describes disruptive innovation as the transformational agent that allows industries to exponentially increase the size of their consumer markets by making products and services more affordable and accessible, and by lowering the bar of technical sophistication needed to provide or use these products and services.¹ Disruptive innovation is comprised of three inter-related primary elements:

- **Technology enablers** that reduce costs and intellectual capital required to produce meaningful solutions
- Innovative **business models** that enable the cost-effective, accessible delivery of solutions to consumers
- Supporting **value networks** (i.e. supply chains, market channels, infrastructure, etc.) that sustain and reinforce disruptive business models. (For additional background, see Appendix A below.)

For disruptive innovation to truly flourish in the health care arena, in addition to the three aforementioned factors (common to all disruptive innovation), a series of reforms need to occur in a fourth dimension—the **social and societal infrastructure** that sustains and facilitates disruption. This infrastructure is crucial in health care, as regulation (CMS reimbursement and FDA approval), reimbursement (third-party payers), ingrained provider behavior (medical education, clinical workflow) and ingrained patient behavior have all worked to dampen or stymie the potential of enabling forces for disruption in healthcare.

For example, due to the presence of myriad regulations and their web of unintended consequences in the health care sector, it will often be necessary to engineer solutions for overcoming, removing or circumventing these obstacles. There is great need for a credible, trusted guide that can transcend the politics of an increasingly partisan and vitriolic Congress.

To this end, the creators of The Roadmap are engaged in an active collaboration with members of Congress on both sides of the aisle, who have enlisted the support of the Forum and offered direct support for the creation and utilization of the Roadmap to effect enlightened and informed bi-partisan policy and oversight.

This unified and unifying document will provide bipartisan cover for collaboratively-minded legislators to dismantle harmful legislation and regulations and their web of unintended consequences, to help remove formerly intractable barriers and thereby ensure a firm foundation for disruptive innovation within health care system in the US, and ultimately throughout the world.

¹ *The Innovator’s Dilemma*, p. XXIX.
Leveraging the Core Disruptive Assets

It can be argued that no industry is more primed for disruption than healthcare. From a performance perspective, the sustainability of the current model of care delivery is failing.\(^2\) At the same time, even a brief survey of emerging impactful technology enablers reveals a wealth of technology-based innovations that possess the potential to exercise meaningful disruptive impact in healthcare delivery (see examples in Table 1 directly below.)

Table 1: Some Emerging Technology Enablers in Healthcare

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<tr>
<th>Technology Enabler</th>
<th>Detail</th>
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<tr>
<td>Circulating Tumor Cell (CTC) diagnostic technology</td>
<td>Advances in microfluidics coupled with novel capture agent technologies are now allowing the isolation of tumor cells from blood samples</td>
<td>▪ Prognostic biomarkers that allow molecular level staging of cancers</td>
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<td>▪ Biomarkers that enable therapeutic response monitoring</td>
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<td>Biosensor &amp; remote physiologic monitoring technology for early diagnosis</td>
<td>Advances in sensor technology coupled with ubiquity of wireless networks allow elegant capture of clinical data</td>
<td>▪ Enables care to be decoupled from hospitals &amp; clinics</td>
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<td></td>
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<td>▪ Transforms approach to care from episodic to longitudinal in nature</td>
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<td>Novel secondary uses of clinical transactional data</td>
<td>As electronic clinical data emerges from encounters, this data can be aggregated and mined for new purposes</td>
<td>▪ Novel disease management programs</td>
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<td></td>
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<td>▪ Accelerated discovery &amp; research</td>
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<td>▪ Longitudinal prediction and ‘early warning’ systems when coupled with biosensors</td>
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<td>Systems biology disease and health stratification diagnostic tools</td>
<td>Advances in measurement capabilities now allow investigation at the length scale of the molecule (DNA, RNA, protein, metabolite) and truly enable precision medicine</td>
<td>▪ Stratification of disease can enable prediction &amp; prevention of illness</td>
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<td></td>
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<td>▪ Stratification of the ‘well’ state allows deep personalization of diagnosis &amp; therapy</td>
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\(^2\) Many metrics regarding the American healthcare system related to cost, quality, and satisfaction have been published elsewhere. If there is one point of consensus in the reform debate, it is that the incumbent system is an unsustainably costly failure.
Yet perhaps no industry has been more resistant to disruption than health care. Its history is rife with efforts that have experienced this resistance firsthand: managed care, preventive medicine, consumer driven health, clinical and personal health informatics, telehealth, direct-to-consumer genomics, etc. Nor is the current industry milieu lacking for attempts at innovation and reform: public sector efforts at Accountable Care Organizations, federal incentives for adoption of electronic health records, health information exchanges, genomic medicine, mobile health, patient-centric medical homes, and many others.

As an innovation sector, personalized health care (PHC) has faced particularly strong headwinds from the prevailing health-care ecosystem. Diagnostic vendors are stymied by the FDA regulatory approval process, life science technology companies are blocked by the social institutions and traditions that underpin physician workflow and practice behavior, advances in clinical and personal informatics have been blocked by patient and provider behaviors, and all have faced the resistance of fee-for-service reimbursement models that enforce the primacy of reactive healthcare. These scientific, technical and social/societal challenges together combine to produce a true “Gordian knot.” Although each challenge by itself might be amenable to solution, the sum of these barriers, incorporated as the existing ecosystem of health care, has thus far resisted all efforts at disruption.

As mentioned earlier, there is no shortage of technology enablers that can key disruption of the incumbent ecosystem of healthcare. However, efforts at creating sustainable innovations at the level of the business model or the value network have thus far yielded little success. Forays into these elements will face severe resistance and pressures of co-option into the existing value network—a phenomenon Dr. Christensen calls “sustaining innovation,” designed to protect the status quo and the interests of industry incumbents.

One clear and compelling lesson of the current health care landscape is that the health care equivalent of “hot swapping” (in computer terminology, the practice of replacing one or more components in a computer without shutting down the system)—trying to apply the innovative enabling technologies needed to disrupt the current reactive system and its existing value network—has been and will continue to be a non-starter. Nowhere in the current network are there provisions for proactively keeping a population healthy, only volume discounts for procedures & transactions.

Instead of “hot swapping,” it is now necessary to erect and validate a new sustaining value network for precision, personalized health care. What business models will work for innovative providers, payers, patients and employers? What facilitating societal structures need to be built? What disruptive technology enablers can be leveraged, and how? The Roadmap for Personalized Health Care will guide the process of answering these crucial questions, and in building, demonstrating and refining this brave new value network.
Governance and Structure
In combating the barriers that prevent the operation of necessary disruptive creation in health care, the Roadmap will engage and integrate the perspectives of world thought leaders in crafting this living online document. Oversight will be provided by the global health care luminaries on The Forum on Personalized Health Care board of directors:

- Mara Aspinall, On-Q-ity.
- Steven Burrill, Burrill & Company
- Clayton Christensen, Harvard Business School
- Leroy Hood, Institute for Systems Biology
- Michael O. Leavitt, Leavitt Partners; Former Utah Governor and HHS Secretary
- Clay Marsh, Ohio State University
- Ralph Snyderman, Duke University and Proventys
- Risa Stack, Kleiner Perkins Caufield & Byers
- Kimball Thomson, Forum on Personalized Health Care
- Eric Topol, Scripps Institute

The Forum Board will provide guidance and direction for the overall roadmap effort, oversee the vision and core identity of the Roadmap and the Summit on Personalized Health Care that will serve as the annual meeting for the Forum, approve the elements of the Roadmap, and lend their credibility and influence to furthering the Roadmap’s purposes.

Under the direction of the Board, the execution team will include the following core members:

- Paul Davis, Healthcare Policy Director, Office of U.S. Senator Orrin Hatch
- Michael Feldman, University of Utah
- Steve King, Innovo Strategy/Innosight
- Fred Lee, P4 Medicine Institute
- Jennifer Logan, University of Utah
- Gerald McDougall, PricewaterhouseCoopers
- Rich McKeown and Natalie Gochnour, Leavitt Partners
- Eve Slater, Columbia University
- Kimball Thomson, Forum on PHC (Board member)

The primary authors of the initial draft of the Roadmap for Personalized Health Care will be Steve King of Innovo Strategy and Kimball Thomson of The Forum on Personalized Health Care, with ongoing strategic guidance and domain expertise provided by Clayton Christensen and Fred Lee.

Following completion of the initial draft, Dr. Christensen and Mr. Thomson will submit the draft to their fellow members on The Forum’s Board of Directors in Q2 2011. Upon
receiving and incorporating feedback from the Board and other key leaders from throughout the health care delivery continuum, the living Roadmap will be placed online on its own dedicated website in late Q3 2011, and will be accompanied by significant public education and media outreach. This and all subsequent iterations of the Roadmap will be curated by The Forum on Personalized Health Care, in close collaboration with the Personalized Medicine Coalition, David Ewing Duncan and the Ewing Marion Kauffman Foundation, and other key industry/movement leaders.

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The creation and implementation of the Roadmap for Personalized Health Care will undeniably be a rigorous, multifaceted and iterative process, and the results it yields will undoubtedly be hard fought. At the same time, this project holds the potential of extraordinary returns on investment and inestimable benefits for humankind.
Appendix A: Core Elements of Disruptive Innovation

Clayton Christensen, co-leader of The PHC Roadmap, describes *disruptive innovation* as the transformational agent that allows industries to exponentially increase the size of their consumer markets by making products and services more affordable and accessible, and by lowering the bar of technical sophistication needed to provide or use these products and services.\(^3\) Disruptive innovation is comprised of three core, inter-related elements:

1. The **technology enabler** reduces the intellectual capital required to provide a value-add solution. Technology enablers simplify and routinize the ability to provide the solution, resulting in decreased production costs, by migrating delivery to less expensive agents. For example, online travel agent sites have migrated holiday booking from retail travel agents to the consumer directly.

2. The **innovative business model** is the commercial strategy that delivers this commoditized solution to consumers in an affordable and accessible manner. For example, Apple applied the technology enabler of the digitization of media to the innovative business model of the online digital media store (the iTunes Store.)

3. The **value network** is the combination of the upstream supply chain, downstream market channels, and the ancillary providers that support and sustain a common business model. For example, IBM applied the technology enabler of the microprocessor to the innovative business model of the personal computer. Lacking the necessary sustaining value network, IBM created its own by both investing in the upstream supply chain (disk drive and operating system manufacturers) and also creating a downstream channel to market (IBM retail stores that sold PCs to consumers.)

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\(^3\) *The Innovator’s Prescription*, passim.