Using the tools of new governance to advance cancer detection, care, and survivorship

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In 1971, President Richard Nixon launched a “war on cancer” with a legislative appropriation of $100 million. Almost 4 decades and $200 billion later, cancer remains an elusive and relentless adversary and is poised to surpass heart disease to become the leading cause of death in the United States. In addition, many millions of individuals have survived cancer but, for a variety of reasons, face a substantially diminished quality of life. The challenges in the fight against cancer are attributable both to the nature of the disease and to the limits of the top-down, expert-driven biomedical model that has been used to wage the war.1–3

In 2009, the Obama administration made cancer a priority in its effort to boost biomedical research as part of its economic recovery plan and budget proposals. This renewed commitment calls for an examination of how expanded cancer research funding might be combined with new forms of governance and regulation to improve cancer detection, treatment, and survivorship.

In our project, “New Governance” represents a framework for policy and program development that attempts to find a middle ground between top-down, hierarchical, and rule-driven strategies and professional self-regulation.4–6 It stresses flexible and revisable standards, broad participation from all interested parties, the synthesis of systematic evidence and experience-based knowledge, and the use of social pressure to effect policy change.7–8

The project draws on the disciplines of clinical medicine, public health, law, and public policy, and involves extensive review of the scientific literature and public and private documents, personal interviews with experts, and legal and policy analysis. It includes the following statements of purpose:

1) We will investigate the conditions under which new guidelines for cancer detection and treatment are likely to be adopted and implemented into standard clinical practice, and the role of voluntary networks such as the National Quality Forum and Wisconsin Collaborative for Healthcare Quality in facilitating this process.9–12

2) We will examine the impact of new participants in cancer research, treatment, and policy such as Livestrong and Susan G. Komen for the Cure and their capacity for bridging apparent gaps between the bench, bedside, and community life for patients, survivors, and their families.13 These groups have raised billions of dollars for cancer research, education, screening, and treatment. They have also become active in recruiting patients for clinical trials, design of research protocols, and lobbying the government for increased research funding.

3) We will focus on how new technology, particularly the Internet, alters the quality of information and communication patterns among patients, clinicians, cancer groups, and health care institutions, and what resources and strategies of new participants have proven most effective in changing our culture and cancer care through social and policy entrepreneurship.14–15

4) We will analyze the strengths and weaknesses of regulatory tools currently or potentially available, such as the use of electronic medical records to advance clinical research, patient surveillance, and follow-up care for patients and survivors; public reporting of cancer outcomes across health care institutions; and direct financial incentives for improved cancer detection and treatment.16–18

Through this research and analysis, we hope to identify how new evidence, technology, forms of participation, and institutional design can best be incorporated into a collaborative system of new governance,
our ultimate goal is to highlight how system-wide thinking and tools can improve the experience and outcomes for both clinicians and patients facing cancer.

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**References**

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