CONSUMER EDUCATION AND PATIENT ENGAGEMENT TO ENSURE THE BENEFITS OF HEALTH REFORM ARE ACHIEVED

The Patient Protection and Affordable Care Act (PPACA) is a substantial piece of legislation that seeks to improve the American health care landscape in a variety of ways. Among other goals, the PPACA strives to increase access to affordable insurance coverage while working towards structural and other changes that would keep future health care costs under control. The most prevalent goal, however, and the one concept that is nearly universally accepted is the desire to improve the quality of care across the United States (U.S.) for all citizens until it meets the highest of standards.

A significant part of the quality concern is how the U.S. can continue to better use prevention and wellness interventions to delay or avoid both acute and chronic diseases. This challenge will only be met if consumers and patients play an integral role in the development and implementation of the policies and programs that are intended to achieve these expected results.

Foundations will likely play a crucial role in bridging the gap between government and institutional change and individuals and families understanding and navigating new programs and systems. As we have seen with the recent implementation of the Medicare Part D benefit, it is often very difficult to translate good policies into efficient and accessible programs that provide their intended benefits to consumers in a clear and concise way. Likewise, all too often health decisions are made without fully informed shared decision making between clinicians, patients, and their families — a frequent commentary of those involved in end-of-life care. Foundations can help by taking the initiative to fund educational tools, campaigns, and programs that will empower consumers and patients and ultimately lead to a health care system comprised of informed people who recognize and value high quality care.

PROBLEM STATEMENT

The success of the reforms found within the PPACA rests on the assumption that consumers and patients will be able to better navigate their way around this new health care system. A related assumption is that they will be able to analyze information, such as quality reporting, in a way that helps them to navigate the system better. These assumptions may be problematic.
Researchers have identified a considerable gap in health literacy between patients and physicians.  For a majority of Americans, understanding and comprehending medical and health information is a challenging task. Additional cultural and language barriers exist and exacerbate this problem for many individuals and families.

The internet has become a source of information for many patients, but individuals searching on-line still must locate and process information, and assess the veracity of what they read. The 'digital divide,' literacy gaps, and language barriers also mean that some of the most vulnerable citizens may be left behind. With these challenges in mind, the PPACA has identified different types of data and information that should be made available and easily accessible to the public. These data, including information regarding insurance options, quality measures, and eligibility will be presented on websites and in print formats. Without appropriate planning and guidance, however, there is the potential for significant usability challenges.

The most common concerns for individuals include the following:

- The website/materials are unreadable because of size and/or typeface issues
- Websites are difficult to navigate; there is too much information provided, and it is too difficult to find answers
- Websites and other material are not available in multiple languages
- Information is not culturally sensitive
- Information is misleading or inaccurate
- Concerns about data confidentiality
- Lack of public awareness about websites or difficulty finding the URL

Many, if not all, of these concerns will also be linked to the public health awareness and education components located in the PPACA. Each and every one of these concerns has the potential to reduce the effectiveness of knowledge transfer and adversely affect the outcomes of these campaigns. If policymakers, administrators, and clinicians intend to truly empower people, they must be certain to educate consumers and engage patients in a consistent and effective manner.

SUMMARY OF HEALTH CARE LEGISLATION

Provisions that will affect consumer education and patient protection can be found throughout the PPACA. The following is a brief summary of those parts of the Act that relate to these two areas.

Title II. The Role of Public Programs
- States will construct new websites that will serve as portals for Medicaid, CHIP, and Insurance Exchange application and enrollment. Individuals will be able to use these sites to quickly determine their eligibility for each of these programs.
Title III. Improving the Quality and Efficiency of Health Care

- A program will be created to increase access to coordinated, community-based care. This program will use community health teams and medical homes and encourage medication management services. A health delivery system research center will be established and it will seek to find best practices that improve the quality, safety, and efficiency of health care delivery.
- The new CMS Center for Innovations will focus on novel delivery and payment mechanisms that will ultimately lead to a better experience for patients at a lower overall cost.

Title IV. Prevention of Chronic Disease and Improving Public Health

- The Secretary of Health and Human Services (HHS) will establish, through a public/private partnership, a national prevention and health promotion education campaign. Federal funds will come from the newly created Public Health Investment Fund.
- There will be a new oral healthcare prevention education campaign
- Several new provisions will be adopted in both Medicare and Medicaid that encourage people to seek primary care services by reducing or eliminating all out-of-pocket costs.
- Medicaid will be required to cover tobacco cessation counseling and treatment for pregnant women
- States will receive grants for prompting Medicare beneficiaries to join programs providing incentives for health living.
- States can be awarded grants to promote individual and community health and prevent chronic disease among persons aged 55-64.
- Through the Centers for Disease Control and Prevention, employer wellness programs will be evaluated. The results will be used to disseminate best practices and an educational campaign will promote the benefits of worksite health promotion.
- New restaurant nutrition labeling standards will be implemented.

Title VI. Transparency and Program Integrity

- New systems will be implemented that force physicians, nursing homes, long-term care facilities and others to disclose relevant information that is currently not required. For example, the Nursing Home Compare Medicare website will eventually have standardized staffing data, certification confirmation, complaint forms, a listing of violations, and other information.
- The new Patient-Centered Outcomes Research entity will conduct comparative clinical outcomes research and provide this information to the public.

Title X. Strengthening Quality, Affordable Care

- The Act requires the creation of uniform standards for financial and administrative health care transactions.
- The Indian Health Care Improvement Act, whose components include increased access, health promotion and education, and innovative delivery models, is funded.
• Medicare is required to pursue prescription drug review through medication management programs.
• The law funds a new Medicare “Physician Compare” website that will provide information about doctors to Medicare beneficiaries.
• Small businesses are allocated funding for grants to provide and promote worksite wellness programs.
• The HHS Secretary will develop a national education campaign for young women and health care professionals about breast health and risk factors for breast cancer.

ANTICIPATED ISSUES OF HEALTH CARE REFORM IMPLEMENTATION

Consumer education is repeatedly mentioned throughout the PPACA. Many education programs and campaigns, such as those directed towards smoking cessation and cancer awareness, have been very effective in meeting their goals. Even so, there are several possible pitfalls that federal, state, and local authorities must consider as they move forward. The overarching issue that could derail implementation is a lack of consumer knowledge regarding the available benefits. Providing this knowledge involves two important steps. The first is raising awareness that benefits exist. The second is explaining those benefits, keeping in mind the audience(s) and any corresponding limitations (for example, a lack of internet access). Similar issues arise when reporting data on physicians, plans, or hospital quality. People must know that the information exists and how to access the information; and they must be able to understand what they are reading. This can be a much more difficult process than one might anticipate.

According to the PPACA, there are three main areas where patient engagement requires improvement: Patient compliance, disease management and prevention, and shared decision making. Each of these areas requires a patient or a patient’s family to be aware of their options and also what is expected from them. Shared decision making is particularly problematic because of the information asymmetry between medical professionals and patients. Constraints, such as time, can often limit the ability of a clinician to provide extensive options along with the pros and cons of each. Some patients may be too sick to fully comprehend their options, while others may not comprehend because of language or other barriers. In terms of patient adherence and disease management, a host of factors, including comprehension, financial constraints, logistical problems, lack of communication, and cultural barriers can lead to sub-optimal results.

SOME OPPORTUNITIES TO LEVERAGE HEALTH CARE FOUNDATION INVESTMENTS

The PPACA contains a multitude of implementation opportunities for foundations to supplement and enhance consumer education and patient engagement. These opportunities include but are not limited to the following areas:

• Website development has the potential to be the most important part of this legislation in terms of reaching a massive audience, with significant ramifications based on the
quality and usefulness of each site. Consumers have been promised websites focusing on:

- State Insurance Exchanges (including plan comparisons)
- State Medicaid/CHIP/Exchange eligibility and enrollment
- Nursing home quality
- Workplace wellness
- Health promotion and education
- Physician quality ratings
- Hospital quality ratings
- Comparative effectiveness of treatments and procedures

Each of these sites will require extensive content building and testing before they are viable. There are many opportunities for foundations to help shape these sites at local, state, and national levels, including the transfer of best practices from the private to the public sector.

- Once this information “goes live”, there will need to be a large public awareness and education campaign targeting consumers. Almost all consumers must learn how to interpret and analyze the data in order to maximize its potential benefits. This seems like a natural place for foundations to intervene.

- Foundations have a long history working with government and private entities on public health campaigns. This should be no different with the PPACA. Whether it be breast cancer awareness, access to health care services, oral health, or nutrition, foundations can make a significant difference in each of these ventures.

- Foundations are ideally situated to help implement many of the workplace health and wellness reforms contained within the PPACA. A careful review of current programs is needed along with the design of new programs sized to fit different types of businesses. Multiple businesses within a state or community can collaborate to share best practices via one overarching foundation grant.

- As we move towards more chronic disease management and patient-centered medical homes, there will be a need for educational and other resources in order to help individuals understand what these changes are and how they will be affected. Foundations partnering with hospitals, insurers, accountable care organizations, and others can provide this type of assistance.

- Patient engagement, particularly when end-of-life issues are involved, is an ongoing issue that will continue to require leadership and guidance. Foundations can lead this effort, bringing together the interested parties and furthering the dialogue surrounding this critical issue.
Within the PPACA, there are several directives to evaluate most of its initiatives, from planning to implementation and beyond. These evaluations will be crucial, telling us what works, what does not work, and why. There is certainly a role in the evaluative process for foundations, and it is likely to be a major one.

This background paper was prepared by Jeffrey Sussman, MPH, PhD Candidate.

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