

REPORT TO THE OBAMA-BIDEN TRANSITION TEAM

TELL IT LIKE IT IS! -- OBAMA-BIDEN HEALTH COMMUNITY DISCUSSION
CHICAGO, IL, JANUARY 5, 2009; 5:30 – 7:30 PM

*This Health Community Discussion was co-hosted by the Coalition for Quality and Patient Safety of Chicagoland (www.chicagopatientsafety.org) and Consumers Advancing Patient Safety (www.patientsafety.org), two Chicago-based organizations. The target audience for this event was key stakeholders in greater Chicagoland who already are active in the patient safety and quality improvement change work. Those stakeholders include among others, **healthcare organization leaders, patients and family members, consumer advocates, employer representatives, physicians and other clinicians, state and county government representatives, educators and other advocates for transformation of healthcare.***

A concern we have as a group is to see patient safety made a priority as Senator Daschle and the Obama-Biden administration take on healthcare reform. The reform framework provided to discussion moderators does not explicitly mention patient safety, although one can see from context that references to healthcare quality and prevention may incorporate patient safety concerns.

By patient safety, we mean elimination of unintended harm caused by errors, omissions or other avoidable failures of the organizations and systems where patients are treated. Preventable harm is a well recognized public health epidemic, estimated by the Institute of Medicine to be the 4th to 8th largest cause of preventable death in the United States. Today in the United States a patient can have an excellent surgical outcome after a highly complicated operation, only to be killed by infection caught in the hospital. Patients with serious illnesses can be accurately diagnosed and successfully treated, but have the benefits of this excellent care undone by taking the wrong medication, or the right medication in the wrong dose.

Our healthcare community discussion lasted two hours. **Fifty-four (54) people participated.** It was a sincere and enthusiastic group of consumers and healthcare professionals who **appreciated this opportunity to contribute to the new administration's planning effort.** During the event, we caucused in small groups for an hour to address the questions provided by the Obama-Biden Transition Team and to solicit insights, stories, and suggestions specific to the interaction among the crucially important goals of patient safety, quality of healthcare and access to healthcare in our region. Each group reported out in a final plenary session. Those comments were captured for this report. Pictures were taken which are attached. Survey responses were captured and are summarized below.

I. Discussion of questions posed by Senator Daschle on behalf of the Obama-Biden Transition Team

1. Briefly, from your own experience, what do you perceive is the biggest problem in the health system?

Discussion: The problem most frequently mentioned in our discussion was the **fragmentation** of the current healthcare systems, which leads to **lapses in care as**

patients transition from setting to setting, makes it more difficult to **compare the outcomes and quality** of care from provider to provider, makes it more difficult to accurately **maintain the patient's healthcare record or ensure its portability**, leads to failure to implement consistently **evidence-based guidelines/protocols**, causes **communication breakdowns amongst the healthcare provider team and between the team and patient**, and requires **wasteful bureaucracy**. The fragmentation makes the system dysfunctional. One small group queried whether we should call it a "system" at all.

Other big problems identified by small groups included:

- Patients have **no "medical home"**
- The fact that **healthcare is seen as a business**, when it should be a service
- **Medical errors** and **poor quality**
- **Infection** and other **healthcare-acquired conditions** that **harm and increase cost to consumers**
- **Cost of care**, and the **disparity** that results
- **Fear of sharing data on quality in a competitive market**, resulting in **inadequate outcomes information that consumers can trust and use**
- **Absence of a modern technological infrastructure that promotes and facilitates safety** in most healthcare facilities
- **Misaligned financial incentives**
- **Lack of teamwork**
- **Employer-based coverage just has not worked, and they really can't make it work**
- Failure to optimize the Institute for Healthcare Improvement's **"triple aim" of the individual experience, health of the defined population, and per capita cost.**

2. How do you choose a doctor or hospital? What are your sources of information? How should public policy promote quality health care providers?

Discussion: Most choose their hospitals based on **doctor referrals** or **location**. Most felt their choice of doctors was **limited by their insurance plan**. Many used the internet to educate themselves about medical conditions, but not to choose providers although there were a few who searched for providers online for elective procedures. People were concerned that there was **no reliable basis for comparing providers**, so what else can we do except rely on referrals, although this often seems like trial and error?

3. Have you or your family members ever experienced difficulty paying medical bills? What do you think policy makers can do to address this problem?

Discussion: Many of us had or knew people who had trouble paying bills. One man was embroiled in a **billing fight between Medicare and private insurance** over who was responsible for his heart surgery that, **so far, had lasted 19 months**. It fell to his wife to do the battling as he recovered, and he was worried about her feeling responsible for the bill. **"It makes me sick all over again,"** he said. Another group focused on the unfairness of the current system, where patients with insurance are often sometimes charged more than those with no insurance or, more typically, those without insurance are charged more than those whose insurers have negotiated deep discounts.

Policymakers should consider these options:

- **Universal healthcare** – many supported this option
- **Single-payor healthcare** – some, but not all, strongly supported this option
- Establishing **a limit for what any patient was obligated to pay**, with assistance to families who exceeded that limit- to prevent bankruptcy and home loss as a result of medical bills.
- **Eliminate the pre-existing condition clause** – it should be declared contrary to public policy.

4. In addition to employer-based coverage, would you like the option to purchase a private plan through an insurance-exchange or a public plan like Medicare?

Discussion: Participants in our forum would like options, including an inter-insurance exchange. **For vulnerable populations, the Medicare program is much better than the benefits they have now.** Again, if options are going work **pre-existing condition prohibitions have to be eliminated.**

5. Do you know how much you or your employer pays for health insurance? What should an employer's role be in a reformed health care system?

Discussion: We had small employers in our group, so **some did have a very good sense of what their insurance cost.** Others didn't know, but **knew it was very expensive.** Many questioned the value of our high cost insurance, given the number of errors and bad outcomes patients in the US experience vis-à-vis patients in other developed countries.

There was divided opinion about the role of employer's, particularly since our groups were very strong on the point that health plans should incentivize prevention. Some felt it **was too much to ask employers to get involved in health prevention**, and that they **should just get out of the way.** Others felt there was a **natural affinity, given employers' self-interest in having healthy employees** and employee families. Still others felt that when it came to prevention and prevention education, **community groups and non-profits would be the most effective.** The anti-smoking groups and disease-focused charities were cited as examples. The distortion of US costs of production by including employer-based health care was noted as adversely affecting the US competitive position vs. other countries that provide health benefits in other ways,

6. Do you receive the preventive health care services you should? If not, how can public policy help?

Discussion: Most felt they **did not receive the preventive services they should**, with **dental care at the top of the list.** We believe that investment in **preventive services will reduce costs overall** in a functional system, reduce some of the access problems and eliminate some of the lifestyle factors that keep vulnerable populations from being more successful and healthy. Public policy can help by:

- **Requiring that preventive services be offered**
- **Incentivizing employers** to offer prevention education through tax credits, etc.
- **Tax credits to consumers** for healthy lifestyles.

7. How can public policy promote healthier lifestyles?

Discussion: The key to good health is not just access to good healthcare, its **access to a healthy life style**. This is encouraged by **creating good jobs, safe communities**, access to **places to exercise**, and **community resources that do public education**. We have models of anti-smoking campaigns that have worked. We need to develop similar campaigns that focus on **diabetes, obesity, diet and exercise**.

II. Discussion of patient safety concerns

The small groups each addressed one or more of the following patient safety topics:

A. How to improve reporting of patient safety events, by both providers and consumers

Discussion: Lack of reporting medical errors is a huge barrier to improving safety. We can't know what our problems are unless we report. Providers are afraid to report to agencies (or even internally within organizations) for fear of recrimination. Patients are afraid to report for fear of getting the doctors, nurses and other care workers who treat them into trouble.

B. How to involve patients as partners in the safety and quality improvement efforts of hospitals, clinics, long-term care facilities and other health service providers; how to get patients and their families truly engaged in ensuring the safety of their own care as they transition from healthcare setting to healthcare setting; how to improve communication between patients and providers on safety issues

Discussion: The healthcare system needs to **invest in patient education**, not just for patients but their families as well. Many organizations exist that can help. **Patients need advocates during treatment and support even after they go home**. Part of patient education is to get them to see that they are **accountable for health through diet and exercise**. Healthcare organizations should **have councils that bring in the patient perspective**.

C. How to increase the use of evidence and evidence-based guidelines in healthcare

Discussion: This is an **entrenched problem that speaks directly to quality**. **Clinician practice gets "frozen"** after training, and new knowledge doesn't get applied even when formalized into guidelines or protocols. The best way to get physicians on board is to **incentivize learning and give feedback**. Learning needs to be **interdisciplinary, with training and access to evidence available to all, not just the doctor** – medical librarians can operationalize this. Technology can play a role as well through **feedback via pop-ups on the computerized medical record**, etc. **Pay for performance** is important, **rewarding those that stay current and follow guidelines**.

D. How to address the obstacles of poverty, discrimination, lack of insurance and other obstacles to getting safe, quality care

Discussion: We do a fair job now at getting primary healthcare services to the underserved, but we are **terrible at delivering quality specialty care**. The employer-based system will not succeed, and **we need universal care with an emphasis on prevention**.

- E. **How to educate healthcare workers about effective ways to reducing the risk of harm, such as prevention of MRSA, addressing growing antimicrobial resistance, performing safer surgery or...; how to educate patients, families or the public about effective ways to reducing the risk of harm, such as prevention of MRSA, addressing growing antimicrobial resistance, performing safer surgery or...**

Discussion: Education is important, but not sufficient. Giving information doesn't change people's practices. It needs to be backed up by **technology to trigger the right actions, barriers to doing the wrong thing** and **behavior triggers for patients/consumers that incentivize or disincentivize**. Education only provides the "why" that justifies the system requirements and barriers make sense.

Story: *A patient with SARS (Severe Acute Respiratory Syndrome) was admitted to a Canadian hospital. The diagnosis was made, risks were known, and protocols existed for managing risk. But there was resistance by staff to taking extreme precautions that might be alarming to other patients. As a result, 258 people contacted SARS, including other patients, medical and nursing staff and family members of patients and staff. 58 people died because existing knowledge of risk was not acted upon. (Note: Discussion organizers have asked the participant who told this story for help in verifying it.)*

- F. **How to respond effectively to patients and families who experience preventable harm due to medical errors, as well as those providers involved in causing such harm**

Discussion: The most important thing to do is prevent harm. But when errors occur, **the system must insist on full disclosure**. Patient advocates can work to ensure that patients get disclosure, and **we should invest in a robust patient advocacy training program using community organizations** to do the training. Providers need to be better listeners, and patients and their advocates need to insist on that happening. The evidence – in our own community, is that full disclosure and apology reduce malpractice claims.

- G. **How to Improve transparency of outcome data available for consumers;**

Discussion: Goal 1 is to **make quality and outcomes data at CMS more comprehensive and accessible** to the public. Goal 2 is to establish is **a centralized website at CMS (or maybe another agency) to which all insurance companies forward their claims data**. This creates a functional ability to achieve Goal 3, which is to have CMS (or maybe another agency) **identify practice patterns, provide feedback to providers, and issue individualized alerts to patients** (universal identifier other than SSN would be needed of course) about transition breakdowns, variations in care or other concerns.

III. Summary & top recommendations emergent from the *Tell it Like it is!* Chicagoland Health Community Discussion

Although we didn't have time to drive to consensus on the ideas that surfaced, judging from tone, nodding heads and applause the following points appear to the discussion organizers to have been the ten strongest ideas or recommendations coming from our group.

They are not endorsed by either the organizers or participants, merely summarized and reported here. We offer them to Senator Daschle and the Obama-Biden Transition team as ideas for consideration.

1. Patient safety should be a visible priority as Senator Daschle and the Obama-Biden administration take on healthcare reform – not more important than access, affordability or quality, but just as important.
2. Eliminate the pre-existing condition exclusion. Make it illegal.
3. Prevention education and services should be a major priority of healthcare reform; existing community organizations are poised to play a major role in the public education end of prevention.
4. Create pathways for patients to report medical errors or other safety concerns. Federal law encourages reporting by providers, but has created no pathways yet for reporting by consumers.
5. It is necessary to create alternatives to employer-based care, especially for vulnerable populations. A single payor system that gets employers out of the picture should be considered. Putting an upper “stop/loss” limit on what any patient/family pays for healthcare is important.
6. Invest in developing patient advocates, using the existing resource of community organizations.
7. Increased payment for performance will incentivize the “unfreezing” of practice patterns thereby encouraging evidence-based practice.
8. There should be a central location for the reporting of outcomes and billing data by all payors, probably at a government agency accountable for using that information to provide feedback to providers and consumers.
9. Education of both providers and consumers about quality of care, prevention of errors and prevention of disease is important, but not sufficient. Change needs to be incentivized and encouraged by technical and systemic barriers to the things acts/behaviors we want to redirect.
10. Prevention of disease and injury cannot be achieved by health system reform in itself; health care reform must go hand in hand with other administration efforts to create good jobs; make communities safe and improve education.

IV. Participants in the *Tell it Like it is!* Chicagoland Health Community Discussion

Carrie Nelson (moderator)
Marty Hatlie (moderator)
Cynthia Barnard (moderator)
Abrar Husain
Amy Simatos
Arnold Widen
Barbara Dershin
Becca Chimis
Brady Luby
Bruce Lambert
Carlotta Rinke
Christine Johns
Christopher Beach
Dawn Niedner
Dennis Skigen
Diana Woytko
Enrique Martinez
Irv Pikelny
Jane Menendez
Janis Ingebrigtsen
Jim Cohick
John Schneider
Karen Latham
Keri Christensen
Laura Botwinick
Lawanda Jones
Leena Nanda
Lenore Henning

Lorri Zipperer
Mark Shields
Mary Driscoll
Maureen Sheehan
Nancy Vlasic
Natalie Garcia-Godos
Patricia Sokol
Paul Teodo
Ralph Fujimoto
Robert Vanecko
Robert Wise
Roberta Rakove
Sandra Magnetti
Scott Kihoi
Shirley Fujimoto
Steve Maxwell
Tessa Burton
Tim Warren
Trish Anen
Bob Long
James Ray
Maureen Drumm
Mary Anne Kelly
Robin De Muth
Jerry Field
Esther Sciammarela

