

## **“IN THEIR VOICES”**

### **Common Ground, Common Sense and Consensus: The Public’s Pragmatic Voice for Reform**

A report on five years of discussions, roundtables, and community meetings to discover the values and concerns that people share about health care reform.

Anna Foucek Tresidder, MPH

Mark O. Hatfield School of Government, Portland State University

Kathleen O’Connor

Founder and Chair, CodeBlueNow!

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*“The most important part of effecting reform is that the movement’s leaders have absolute belief that compromise is possible and reform is doable.”*

**Our Mission:** *Create strong public will for change by engaging the public in designing, shaping and promoting a template for a new health care system.*

## **Our Work, Their Voices: 2003-2009**

A reformed health care system must respond to the values and concerns of the people served if it is to be successful and sustainable. We offer this paper so others can be inspired to continue mining ideas for legislators, policy makers and all of us who care about the health and well being of our people.

For the past five years, CodeBlueNow! staff and volunteers met with all kinds of people in church basements, libraries, grange halls, at their jobs, in their living rooms and at their kitchen tables to learn what is important to them. We found practical people who care deeply for their families and communities and want a practical health care solution that meets their needs.

Our work began with a national contest asking people to design a new system. Over 100 proposals were reviewed and judged. We found thoughtful, analytical and practical ideas and insights. Included herein are some brief summaries with quotations from those proposals, as well as direct quotes from people who participated in our market research surveys.

### **Passing the Baton — From People to Policymakers**

We found that more common ground exists on key elements of reform than we hear in the press. We also found that we can find consensus when the reform conversation is changed from a political one to a problem-solving conversation. As we conclude our field work, we offer no specific solution; instead we offer conceptual values which can serve as benchmarks to judge reform proposals.

### **From Vision to Viable**

I am old enough to remember President Kennedy's challenge to us to go to the moon. I am old enough to remember when my school was the first in Virginia to be successfully integrated exactly fifty years before Obama was inaugurated as our 44<sup>th</sup> President. I remember newspapers with "help wanted - men" and "help wanted - women" when I graduated from college and not being able to have credit in my name, even though I held a job and my husband was a student. I know large social change is possible but that it does not emerge from fear. It is embodied by vision born in hope and courage. While there will be much fear mongering in the debate ahead, we offer these principles and values to keep a hopeful steady course.

*Now is the time for all of us to speak up. Please add your voice to this yeasty mix. It takes courage to speak up. We hope hearing these early voices will lend you courage to add your own.*

Kathleen O'Connor, Founder, CodeBlueNow! [www.codebluenow.org](http://www.codebluenow.org)

## In Their Voices: Common Ground, Common Sense and Consensus on Reform

The following ideas and themes emerged from five years of grassroots work with the public. These insights are presented here in the voices of those who spoke them.

### Accountability

The public desperately wants accountability inserted into the health care system. This need ranged from wanting information on care and treatment standards, options and costs, to creating new management structures so people could have a voice in the system. They want cooperation from individuals to take care of themselves and consider themselves part of a larger wellness community. Accountability is a strong core value that emerged consistently throughout this process.

- *“Define public and private responsibility to meet goals. Define principles to support those goals. Use patient-centered care to support those principles. Create a new health care commission managed by a new board composed of Health and Human Services and Social Security Administration. Then create a new board of trustees of consumers and providers.”*
- *“...so much emphasis has been placed on medical system outcomes that a substitution of goals has occurred; access to medicine rather than better outcomes has become the objective of federal policy.”*
- *“Consumers should be ‘praxers’ — practice good health habits, and axe bad health habits and providers who do not serve them well. They should exercise all their options for improving their health and the health of children in their family.”*
- *“Create color coded health ID cards. Blue—general access to the system; Green—electronic medical record access (provider cannot access them without your card); no tobacco purchases allowed. Red cards are for the purchase of tobacco products, paid for via payroll tax along with a corresponding insurance tax.”*
- *“It is not enough to create the funding sources, health care reform that provides access to all Americans needs to guarantee the public that those funds entrusted to the new health care board can only be used to deliver care and administer the program.”*
- *“Accountability of the people running the system, whoever that might be. If there’s a problem with regulating the coverage for people; just to make sure some is held accountable.”*
- *“Personal responsibility for your own health, access to information and education, and shared financial responsibility.”*

- *“Accountability. There’s got to be a lot of money involved. It has to be watched. Input from medical professionals. Not control but input.”*

People wanted to optimize incentives for wellness and create financial rewards for good health practices and wise health behaviors.

- *“Currently patients have little involvement in their health care once they have initiated an episode. It is not surprising that they feel they have little control or responsibility over their care.”*
- *“Remove vending machines from schools. Control alcohol and smoking placements in movies and use more public air time for public education.”*
- *“....if we can use public dollars to bail out corporations or to loan foreign countries, we should be able to at least advance our working citizens enough to help them when the chips are perhaps at their lowest.”*
- *“Funding CUB (Common Uniform Benefit) must not be tied to a political administration. The benefit would be legislated and would continue regardless of the result of an election and the whim of a new administration.”*

## Affordability

Cost is a critical concern. People fear bankruptcy from health care costs. They see friends and family struggling without insurance to help cover costs of necessary care. Many of us are ashamed that we do not care for all our children and our elders. Working people should be able to afford the cost of care. Those who cannot help themselves should have an adequate safety net to assist them through trying times. People believe we are pennywise and pound foolish by not focusing on wellness, prevention and health promotion.

- *“If incentives can be tied to insurance premiums in health care based on a patient’s adherence to factors that are proven to increase or decrease health risks, there is significant potential for the burden of health care and its associated costs to be reduced.”*
- *“A health care system without public health is like a ship without a rudder....Adequate funding of public health will substantially reduce expenditures for therapeutic medicine.”*
- *“Poverty: A new system should focus on the causes of illness.”*

- *“The success of public health helps to keep personal health affordable, since reducing population risk even a small amount can have a large impact on aggregate personal health care expenses.”*
- *“Pay women \$10 for each prenatal care visit and pay parents and guardians \$10 for essential immunizations per child.”*
- *“Develop a system of ‘prospective’ care targeting risk factors for population health. Actively engage physicians in identifying risk factors and create incentives for coordinated clinical and social care.”*
- *“Have all health care coverage start with pre-natal care and well child care, including pediodontics.”*
- *“The system does not incentivize individuals to live healthy lifestyles. Having multiple insurance companies that people transfer between does not incentivize the insurance companies to focus on prevention. The amount spent on the last of life is far too much. We should become more comfortable with death as a culture.”*

While the national health reform debate is trapped in a lockjaw fight between single payer vs. marketplace approaches, the public is far more pragmatic. They want a system that works and are not wedded to one particular form of financing. Most want shared responsibility and would modify the current system rather than start from scratch. (See Shared Responsibility)

- *“Rather than tearing down the existing system....incremental changes, developed honestly, are the only way to go to where we want to be. Otherwise, the political pain is too great and nothing can move forward.”*
- *“Along with a new model for health care delivery, there is an equal need for a group of strategic planners to mount an offensive against the tactics put forth by those opposing various elements of change....as momentum moves toward change, I expect a rear guard action by special interests that will advocate small steps that only nip at the edges of the health care delivery system. Their timidity can be overcome by strong voices melded out of advocates and think tanks now promoting their own opinions and solutions. We badly need consensus.”*

One proposal focused on simply covering all hospitals costs as a means of controlling costs. It argued, given that two-thirds of hospital costs were already paid by Medicare and Medicaid that we could cover the balance of the costs by a marginal increase in the FICA tax. (See Strong and Unique Points).

While some people advocated for single payer and others for health savings accounts, the majority focused on different ways of organizing the system to bring down costs. Most of the proposals would reduce costs by rationalizing and simplifying the system in its current form. They insist that care is more efficient and tied to some clear care standards.

- *“A health care system without emphasizing public health is like a ship without a rudder.... Adequately funding public health will substantially reduce expenditures for therapeutic medicine.”*

Numerous other proposals discussed the importance of revising medical malpractice as a way of lowering system costs by reducing the impact of defensive medicine practices. None removed the patient's ability to sue, but most stressed mandated mediation first and some limits on non-economic damages.

## Choice

If accountability and affordability are central to their thinking, choice is just as critical. People thought a new system must let them keep their choice of health plan, provider and benefits. They also wanted complementary and alternative providers in a benefit package.

- *“I see only futility for advocates of any model that tries to cram a one size fits all universal health care down the throats of all Americans....Many in the US workforce feel they have worked hard enough for the health benefits they receive from their employer and their union.”*
- *“I see absolutely nothing to be gained in having the public sector take over all administrative functions in the new US health care system....millions of dollars of excellent computer systems and the trained staff to operate them are in place....”*
- *“....because a single risk pool would probably be the political death knell of any reform proposal....targeting a smaller group of individuals who were underserved ...bringing them into a single pool voluntarily.”*
- *“Freedom of choice of doctors, hospitals and types of health care.”*
- *“Some alternative medicine is not covered under regular insurance, and it should be.”*
- *“I don’t want it going national. I don’t want the government telling me what to do, what doctor to go to, or what operation I can or can’t have.”*
- *“Basic access to all Americans for all Americans. Shared financial responsibility plan between the individual and employer. More affordable options for advanced health care like specialized treatments beyond the basic access.”*

## Equity

The public also feels strongly that we need to cover everyone and that we need to play by the same rules or at least reduce the burden of regulations.

- *“Equality. People who need it can’t get it. People who have it don’t really need it, to the degree that they get it.”*
- *“Universal accountability, universal access and consistency of quality. Universal accountability means same standards on how money is spent are applied everywhere. Quality means there is no high or low end, it is the same medical system.”*
- *“It’s very expensive and some don’t have access to health care because it is so expensive....Because it’s Capitalism, and it’s a battle of the fittest, a certain percentage falls behind. Capitalism doesn’t always serve the common good.”*
- *“There are too many people having to go without health care or cannot afford it. I think we are in a world of hurt as far as leadership in this country, as far as people caring about those who don’t have access.”*
- *“We don’t take care of our low income people. I think it is a national disgrace.”*
- *“The fact that everyone isn’t covered. It’s a lot of political chicanery. They battle to have universal health care, and there are many, even children, that aren’t covered. Those without coverage are forced into ER and pro bono care in hospitals. That’s not fair and it’s expensive. Ninety percent of the people don’t have the coverage I do. I’m lucky.” Washington voter.*
- *“If we can use public dollars to bail out corporations or to loan to foreign countries, we should be able to at least advance our working citizens enough to help them out when the chips are perhaps at their lowest.”*
- *“It should be fair to all. If you break your arm in Chicago, the care and the costs should be similar to California. Sometimes people are denied coverage. There are people that have cancer and their policies have run out, leaving them destitute. That shouldn’t happen.”*
- *“Equality. Because you have more money doesn’t mean you should get better health care.”*
- *“Patients should be penalized for not following doctor’s orders, such as not getting a mammogram or ignoring preventive tests, such as colonoscopies or other specific orders for care.”*

## Information and Transparency

People want to know that the care they are receiving is based on some standards. They want understandable information on their diagnosis, treatments and outcomes.

- *“Expand access to computerized diagnosis and tie to ‘ask a nurse’ and locate this in libraries or other easily accessible places. This improves easy access to basic information.”*
- *“Change medical education and tie it to outcome metrics.”*
- *“Create a national database on outcomes and clinical trial research and use NSA, DOD and ISO techniques to eliminate errors.”*
- *“Patients have performance data on all doctors and insurers publish basic data on doctors in system.”*
- *“We could save \$300 billion from regulatory simplifications. Appoint a task force to remove excesses and redundancies from various regulatory levels....set and maintain a level of administrative costs.”*
- *“Cost. I am going to have a hip replacement and the doctor is only getting \$2,500 and I am paying \$85,000 for the entire operation. Where is the money going?”*
- *“The billing system. You can never tell how much money you owe. There’s a whole lot of living wage employment that we have to support to find out how much it is. I know someone who had to wait until a collection agency called to fund out how much they owed.”*
- *“Establish uniform minimum benefits. You have to cover mental health, preventive care and things that are not normally covered now and catastrophic medical expenses so it’s not borne by the individual and the employer.”*
- *“Transparency. Making sure the money is spent on health care and is not lining someone’s pocket.”*
- *“There are too many choices for coverage and treatments. The ‘product mix’ does not focus enough on which is the best form of care.”*

## Shared responsibility

Many different ways to manage health care were introduced, but most people basically retained a shared responsibility in financing and management. The proposals outlined different ways to organize and manage a modified system. Models ranged from FEHBP (Federal Employee Health Benefit Plan) and Federal Reserve Board to public education and public utility models. Most models inserted a much broader role for the public in governance.

- *“Create a new Federal Health Insurance Corporation organized through state purchasing cooperatives that are managed by local trustees.”*
- *“Expand Medicaid for everyone up to 300% of the federal poverty level; create an employer buy-in provision and create a new private market for those above 300% of poverty.”*
- *“Create a new national board that sets policy and defines benefits and monitors states and sets regulations. Use private insurance for benefits that are not covered in core benefit package.”*
- *“Create a new National Health Commissioner with county advisory boards and regional public health boards operating the community health systems.”*
- *“Create an integrated medicine wellness co-op that is open to individuals and employers with funding from dues. There would be a tiered health care delivery system—local clinic, medical center, regional hospital and national institute for research.”*
- *“Create a federal purchasing alliance to purchase pharmaceutical products and equipment for doctors and hospitals.”*

Other ideas included appointing a Consumer Health Advocacy Organization with a Governing Board appointed by Congress and the President.

The salient point here is that the public is pragmatic and flexible. They want a problem solved and are not locked into the diametrically opposed camps of single payer vs. marketplace. That is a doomed debate which will ultimately cause the American public to tune out and regard it as simply politics as usual. Reframing the debate to a practical one using these principles would go a long way to save the day. The public consistently told us they would not move until they can see how a system would work for them.

## Efficiency

Considerable attention was given to the efficiency and quality of care that would come with the broader use of information technology. Efficiency could be a cost-reducer, time saver for providers and patients, as well as establishing more environmentally sound practices throughout the system.

- *“Make all billing and payment electronic. Use a repository of health care data to analyze and educate on practice patterns.”*
- *“Design an Amazon.com-type of web based platform for US Health Care for universal portability, privacy, education and interaction.”*
- *“Create a national computerized data base that consumers can access online that identifies criteria for selecting a health care provider (from number of procedures performed per year, number of lawsuits, etc.)”*
- *“Create a national computerized data base of services and tie to the anticipated outcomes/treatments to those services to create an automated learning community and have data supported medical decisions analogous to computerized chess and complexity science.”*
- *“Develop a software package physicians can use to give patients a ‘health estimate’ at the end of a diagnostic session which includes a good faith effort of cost of care over a two year period. Issue a competitive bid to attract software developers and use decision-tree or critical path analysis. The software must be able to accept downloads and upgrades and help physicians compare their decisions with other doctors and medical procedures. This has the advantage of having physicians working with other physicians. Physicians are already used to educational scrutiny by peers and faculty, so this should be done in conjunction with medical schools.”*
- *“An Electronic Patient Management System (EPMS) provides screening/preventive reminders to patients and sanitized data to the healthcare information infrastructure knowledge base. The patient should be able to access their medical information remotely.”*
- *“Change medical education and develop outcome metrics.”*
- *“Facilitate groups vs. individual practices; increase availability of interactive medical software programs. Doctors must complete 50 hours of continuing medical education each year and spend three months every seven years in an appropriate medical school residency. Use physician assistants for routine procedures such as colonoscopies and endoscopies.”*
- *“We firmly believe that like many other industries, with quality analysis and assurance programs, healthcare costs can be decreased while quality improves.”*

## Protection and Security

People are worried about the impact of health care costs on themselves and their families. They do not want to have to choose between paying for healthcare and paying their mortgage. They are terrified of costs and feel trapped by the fear of losing their benefits. Security is deeply personal to them.

- *“It’s frightening where I am. The thought of having to provide my own insurance is daunting. It is my responsibility as a husband and a father. My wife is a stay at home mom.”*
- *“Categorize health care into essential, preventive, catastrophic and elective tiers, with essential, preventive and catastrophic covered for all residents.”*
- *“Employers pay for catastrophic coverage and deduct amounts from unemployment compensation or other federal payment.”*
- *“Keep a private market, but create new universal catastrophic coverage using the Federal Employee Benefit plan as the management model.”*
- *“Have the medical professions define the standards of care and penalize their members who consistently fail to meet them.”*
- *“Young people don’t have access to Medicare like we do and it’s a terrible expense to them. If they live in a rural area like we do and there was an emergency with one of their children, and had to be helicoptered out, it would be a terrible expense.”*
- *“It’s complicated. The paperwork has gotten terrible. I had a stack of bills an inch thick and trying to match the bills with the insurance was too much. When you’re not feeling good, you don’t want to do that.”*
- *“When my husband dies, I won’t get it anymore, so I’ll have to go on Title 19. That’s the way his company works. When he goes the insurance goes. I’m trying to save enough money for when that happens, but it will be hard.”*
- *“In the event that you need a real emergency transportation to a health facility, it is not covered by Medicare or supplemental insurance. I just had to pay \$12,400 for an emergency helicopter ride to put a stent in my heart and I had to pay for the ride.”*

## Strong and Unique ideas

Many of the proposals introduced some unique ideas. These ideas reflect the very practical nature of the American people who just want a health care system that works and would consider a range of ideas if they addressed the values and principles outlined above.

- *“Hold a national public education campaign before a new program is implemented to educate all the stakeholders about the new system in an understandable and clear manner, demonstrating the benefits of the new system and identify shortcomings.”*
- *“Create learning communities with complexity style software focusing on treatments and outcomes. Tie outcomes to performance and payments.”*
- *“All patients along the continuum of care would participate in longitudinal studies. This data will add to the body of knowledge as large clinical and administrative data sets are used to inform clinical and financial decisions.”*
- *“The subject of death should be given more time in medical education....Hospice care should be heavily promoted instead of being’s America’s best kept secret.”*

### Community Cooperatives

One proposal advocated creating community cooperatives that would contract with local and regional providers. These cooperatives would be possible if Congress amended the VEBA (Voluntary Employee Beneficiary Association) provision of ERISA so any employee, not just those “engaged in the same line of business,” could join the co-op. It would allow the health savings accounts to roll over annually and would clarify the use of funds for nontaxable wellness, sickness and accident benefits when provided by a 501(c)3.

### Vocational Villages

The winner of the contest, Douglas Benn, proposed creating vocational villages to address the problems of low income workers and the need for health care professionals. While his proposal focused solely on low income single mothers who would live together in a ‘vocational kibbutz’ where they shared cooking, cleaning, and childcare while they had grants to local community colleges so they could study to be nurses. Upon graduation they would work in public nursing homes or hospitals for set number of years.

### Cover Hospital Financing: Medical costs coverage tax

Arguing that the bulk of health care costs are hospital costs, and that nearly two-thirds of those costs are already covered by Medicare and Medicaid, that all we would need to do is to see that the other costs are covered.

- *“We could change the FICA tax to a medical costs coverage tax shared by employer and employee. Based on insurance costs of \$8,000 per person, this would be a weekly cost of \$156.86 shared by employer and employee. For a minimum wage employee, it would be \$13.21 per \$100. The employer would be free to add more benefits. The system would be managed by an agency like the GAO, and a health care Comptroller General would be appointed with a 15 year term.*

*All claims would be paid twice a month electronically. There would be national standards for licensing and review and all claims would be processed using social security numbers."*

Other proposals thought \$300 billion could be saved through regulatory simplification, eliminating duplication and thoughtful reduction. Another suggested using a provider tax, like the State of Minnesota does, to finance the care of the uninsured. The provider tax was suggested in part because it provides incentives to the provider community for patient health outcomes and rewards efficiency.

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These ideas and insights demonstrate that the American public is a practical and thoughtful group that simply wants a health care system for all that provides quality care. They want a system that is accountable, affordable and equitable. Overall, they do not want a government run health care system, but they want one that provides access to health care when they need it. They are concerned that people cannot access services when they need them, because it is not affordable or their employer does not offer adequate coverage.

The federal government in Washington, D.C. is struggling to find compromise, consensus and common ground. The American public at large has been thinking about health care for a long time and has many solid conclusions. If many of the points outlined above were included in a public debate it would assure the public that policy makers are listening to their concerns, not just the Beltway stakeholders.

We encourage community groups and other advocates to use these principles as benchmarks for reform. We urge you to add your voices to the many who simply want a health care system that works for them not against them. By adding your voices to these and others we can create the public will for reform.

- *"Will we remain too fearful to change or will we dare to paint a new landscape for health care in America? The re-making of the health care system will require wisdom, courage and altruism... It will also require the absence of fear."*

## **Sources**

Many of the quotations in this report were extracted from the 109 proposals that were submitted in the 2003 “Build an American Health System” Contest. The names have not been included in these materials because the proposals were submitted to the judges in a blind review. We have the proposals, and should others be interested, we can share those proposals if you contact us.

Other quotations came from direct responses to some open ended questions in our market research survey of Iowa and Washington State Voters conducted by Gilmore Research Group in summer and fall of 2007.

The market research surveys are on our website:

<http://www.codebluenow.org/voters-platform>

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