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The President of the United States
The White House
1600 Pennsylvania Avenue NW
Washington, DC 20500

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Subject: Curing our Ills

Mr. President,

Welcome to Washington. I hope you and your family are well. In memory of my father who died 11 years ago today, I want to share my thoughts with you about improving our country and curing our ills.

I am not an expert in health care. I only have a few personal experiences on the topic beyond what I suspect is routine to many people. Raising a child with an incurable disease and making the decision to remove the feeding tube on my father because of the limits of our medical knowledge are two examples for me. And while my other experiences are not extraordinary compared to many others in our country and around the world, I would like to share my thoughts with you about how to fix the health care problem. As I watch you and our other leaders in Washington, D.C. discuss the future of health care, hear you express shock at numbers of uninsured, and set goals for electronic records, I want you to know that from my view something important is getting lost in all the talk. I know you are just coming onboard and putting together your administration, so I wish you well and hope you will take a brief moment to consider this idea.

My idea is a 100 year plan. And like everything else we have to start somewhere, so here it is:

The goal of national health care should be to maintain health and quality of life. It should not be to insure everyone or make records electronic. Those are simply bandages around much bigger wounds. The problem is access to care; the problem is access to cures.

If you did a poll, my guess is that most folks agree that cancer is a bad thing, so let's start there as an example. We can't fix everything at once and while I'd love to see my son's diabetes cured first, we all have to set priorities and make sacrifices. We can fund a lot of things and get a little, or we can fund one thing and get alot, So let's fix cancer and then figure out what comes next.

First, we need to define what cancer is and is not. That shouldn't be hard, I mean, either you have cancer or you don't. Next, fully fund all treatment with taxpayer dollars for every American that has cancer. This will have two immediate effects. First, everyone with cancer will have insurance and second the risk for insuring individuals who might get cancer is removed from insurance companies, thereby dropping the premiums on existing insurance policies and making insurance more affordable and possibly accessible to others. This could take a little time to sort out, but I think in the long run it will work.

The second step is to fully fund cancer research by making the eradication of cancer a national priority. Now, I'm not a scientist but I'm sure you can find a bunch of experts you can put into a room to assemble a plan to do this. Just get really smart people and not politicians and lobbyists. We put a man on the moon when no one thought we could, can we not organize around a goal like curing cancer and then do it?

The consequence of achieving a cure for cancer will have two immediate effects. First, we will gain knowledge about other diseases and possibly stumble across new cures along the way. Second, once cancer is cured it won't cost us to treat it anymore and the cost of treatment goes away. So, we end up with a cured disease, extra knowledge to apply to other diseases, no cancer related deaths, and of course lower private insurance costs along the way. Not a bad place to start.

After that, we pick the next disease, follow the same approach and maybe in 100 years if we are wise and patient, all people will have access to the care they need when they need it, and all disease will be cured. Isn't this really the way to save the cost of health care in the long run? Isn't this how we achieve the goals of providing health care to maintain health and quality of life? Would this not free up resources for other things – like caring for all the elderly with dignity, compassion, and respect? A long term rational approach to solving problems could ignite from this approach and energize many generations of Americans and others around the world toward a common vision and help us solve many of the other big problems we face in the same way. The long view is always better in the long run.

Finally, I have a few thoughts about your proposal for electronic health records. I am a technologist by trade so this is closer to my area of expertise, although I don't work in the health care field. Futurist Joel Barker might say I work in the "Verge" of innovation. However, if your objective is common electronic records then in my view the effort will fail like so many others have in the past. The objective should be making health related information available to those who need it when they need it, not constructing a form everyone can agree on. Patients, doctors, legitimate researchers and organizations like the CDC probably have the strongest need to know some information and there are likely many others. Trying to rationalize all these uses to a common form is futile. Patients and doctors want information for treatment, and researchers want information to analyze. After you cut away everything wasteful about the way we usually start automation in the federal government today, by beginning with the form, we're left with the real challenge of managing the access to data which is the third step to getting access to care.

What I propose you do, Mr. President, is have our government address the barriers to sharing the information to include the laws governing patient privacy and the use and protection of health related data. Congress passed legislation over the last decade, but a much bolder approach is needed. We must be able to establish universal interoperability protocols and standards that explain the rules for sharing data between patients, doctors, researchers, insurance companies, and others in such a way that it is simple, understandable, and executable in an automated environment. We must treat all health related information as an artifact of knowledge and not a data element or attribute to be used in a form. Who cares if one hospital uses one form in their computer system and another hospital uses another? Technologically it doesn't matter, and just like the Internet manages domain names around the globe, we can manage access to health data. I won't go into all the technical details here about how this would work, but there is a way to do it and do it right. And by taking a fresh approach, you will pave the way for interoperability and knowledge sharing. You will pave the path to access. Please ask yourself, Mr. President, is it really important to have one standard way to catalog a particular illness on a form right out of the gate, or is it more important that a patient seeking treatment for an illness have access to a doctor that has access to the information they need when they need it to provide treatment or a cure?

I can share more about this Mr. President, but I have taken way too much of your time. The bottom line on electronic records is that for over two centuries our government has used the paradigm of forms for data collection and standardization, and the approaches I have seen on the HHS and Department of VA websites for electronic records follow this outdated approach today. The bureaucrats are stuck in the past.

We need new thinking on data interoperability for health, and the approach to standardizing the data formats is not the place to start. If it is, with all due respect Mr. President, that is where it will end too. I say we need to create an environment to succeed by tackling the really tough legislative and constitutional issues of health data sharing and use first, and let the evolution of a standardized electronic form be a consequence of that effort - not the beginning. I predict that if you follow the form first approach like we have for over two centuries, nothing of national use will be implemented in five years and I will be writing this letter again to the next President.

Please call me if I can help. I think if your health czar or whoever you pick to improve health care and access to electronic information really wants to be successful, then getting a different point of view other than the ones the health industry wants you to have right now might just be what the doctor ordered. Health care for all Americans should be something real and not something else.

Thank you for your time Mr. President. I wish you lots of luck.

Respectfully,

John Stuart Edwards