

Crossing the Quality Chasm Summit: Redesigning Care and Improving Health in Priority Areas January 6, 2004

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**Crossing the Quality Chasm Summit:
Redesigning Care and Improving Health in Priority Areas
1/06/04**

2

DR. REED TUCKSON: -- Good morning. Thank you. My name is Reed Tuckson and it is my privilege to represent the Quality Chasm Summit Committee. And on behalf of them it is my pleasure to welcome all of you to the First Annual Crossing the Quality Chasm Summit.

As you are by now aware this summit is focused on implementing the vision for a reformed healthcare system as defined in the landmark 2001 IOM report entitled Crossing the Quality Chasm: A New Health System for the 21st Century. We are indebted to the forward thinking committee on quality of healthcare in America chaired by Dr. William Richardson for what I think we would all acknowledge has been a truly transforming report.

Our work together over the next two days is a direct and a logical extension of a body of work that the IOM has been devoted to for several years. And I think we can expect for the next many years.

To place this first annual summit into that context of the IOM's work it is my pleasure to introduce Dr. Harvey Fineberg, President of the Institute of Medicine. Harvey.

DR. HARVEY FINEBERG: -- Good morning, everybody. It is a pleasure to see you all here. I can hardly imagine a more exciting or pertinent way to begin 2004 than with this particular conference. You are here because you have a very special role to play we believe in helping to move forward the

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**Crossing the Quality Chasm Summit:
Redesigning Care and Improving Health in Priority Areas
1/06/04**

3

nation's agenda on improving the quality of care.

I want to express to Reed Tuckson and the entire committee who helped organize this meeting my deep appreciation for the work that you did. To John Lumpkin and the Robert Wood Johnson Foundation, Paul Tarini, other staff from that Foundation who helped support financially and programmatically the ideas that are embedded in this meeting. I want to express my sincere appreciation to you. And most of all, I want to thank each and every one of you who are here because you represent 15 different communities around the nation who are in the vanguard of thinking and commitment to advancing the agenda on quality of healthcare.

As Reed pointed out, this builds on the report of 2001, Crossing the Quality Chasm. But in the intervening years there have really been a series of efforts that have helped lay a foundation to lead to this particular gathering.

For example, in recent months we released a report on information systems and the national health information infrastructure and the electronic health record that is a fundamental building block of quality. This was accompanied very recently by a report on the environment for nursing and the work environment for nurses and how critical that is to improving the quality of care.

We also have had a series of efforts around improving education for health professionals at every level and

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**Crossing the Quality Chasm Summit:
Redesigning Care and Improving Health in Priority Areas
1/06/04**

4

particularly looking at ways of working together in education as well as in practice across the several professions. And we've had studies that looked especially at the roles of government as leaders in the delivery of service, in the support of service, in the regulation of service for activities that can advance the quality agenda.

But there are two particular pieces of work that I wanted to highlight as backdrops to our discussion today. One of them was the report that was called Priority Areas For National Action that identified 20 different areas mainly around chronic conditions that were targeted as especially appropriate for advancing the quality agenda.

George Isham and his committee who prepared that report have done us a great service in laying out the criteria that determined which of the many possibilities deserved this kind of special attention. And the five particular areas that are the focus of today's discussion derive from those 20.

Secondly, just over a year ago we released a report called Fostering Rapid Advances in Healthcare. This was a very rapidly assembled report at the request of Secretary Thompson to try to identify opportunities for advancement at the local and state level. And putting that together in terms of the opportunity for demonstration project at the community and local level, with the foundations of principle laid out in the core report on crossing the quality chasm with the specific

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**Crossing the Quality Chasm Summit:
Redesigning Care and Improving Health in Priority Areas
1/06/04**

5

elements that have been advocated around measurement, around information technology, around the work environment, around education, we believe we have a lot of the pieces in place to help really advance the agenda.

But what this meeting is about is about action. This meeting is about implementing change. This meeting is an effort to bring together agents of change who can work together in their communities and with their colleagues to make a health system that is safer, more effective, more efficient, more timely, more patient centered, and with greater equitability - all of the primary goals of a system that is high quality.

I am really looking forward to learning more of the results of your work through this day and I hope that at some point perhaps several years distant, we will be able to come back together to report on what has been accomplished and what can then be the next phase of achievement.

Each of the communities that are participating are a building block. Each is an experimental center. Each is a place of innovation. And if we can take advantage of our mutual learning in the course of this day to renew our own sense of possibility and direction then the objectives of our meeting will have been accomplished.

A lot of work preceded the first work at the Institute of Medicine on quality. A lot of work will follow from this gathering. I am very grateful to each of you for your

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**Crossing the Quality Chasm Summit:
Redesigning Care and Improving Health in Priority Areas
1/06/04**

6

willingness to devote the energy, to put forward the determination, and to dedicate your time and effort to this very great purpose.

So thank you all very much. I wish you every success through the day and beyond. And I want now to call back Reed and thank you for your leadership, Reed on this meeting.

DR. REED TUCKSON: -- Thank you so much. Thank you. Thank you so much.

We really do envision this summit as a practical and a tangible next step in the process of crossing the quality chasm.

We are greatly indebted to the Robert Wood Johnson Foundation as the sponsor for this gathering. And we anticipate that the insights that we collectively develop over the next two days will stimulate the necessary resources for a second and a third and a fourth summit in future years.

It is my pleasure to introduce Dr. John Lumpkin, Senior Vice President of the Foundation to bring us greetings from the Foundation. Dr. Lumpkin.

DR. JOHN LUMPKIN: -- Good morning. It is a pleasure to see all of you here this morning. It was a thrill once again as I do quite frequently, to come down to Washington. And I'm always struck by the fact that Washington is two towns. There's the Capitol complex and then there's the rest of the city where people live in their communities and within those

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**Crossing the Quality Chasm Summit:
Redesigning Care and Improving Health in Priority Areas
1/06/04**

7

communities where change is going to occur is in those communities where the vibrant life of Washington, D.C. occurs.

And as I was thinking about these two, you know, this contrast between the Capitol complex, I was going back to the work of The Tale of Two Cities and how it began. "This is the best of times. This is the worst of times."

This is the worst of times because we're the wealthiest nation in the world, yet 44 million people are uninsured. Quality as all of us have known, in the recent report that was in the New England Journal of Medicine by Elizabeth, Dr. McGlynn and others showing that when you look at records the quality is pretty much at the toss of the coin. About 50% of the times our quality guidelines are followed.

The disparities continue to exist. For instance, in taking the area of asthma, when you look at a measure of the quality of asthma care for children is whether or not children are followed up within a week after being hospitalized in the Emergency Department. When you see that disparities exist between people of color, in fact, African Americans are followed up after visits to the Emergency Department, their kids are followed up about half the rate of the white population. But what also strikes you is that the rate in the white population is only 40% of the guidelines.

And in fact, as Michael Rossman, I think he's here somewhere, leaned over when we saw this result. He said, "You

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know the problem is that is that it stinks for everybody.”

This is the worst of times because there's variations of costs and our healthcare system certainly continues to be in crisis. Variations in quality like who you are, where you receive your care, and what your, who your providers are.

But as you go down the list of all the problems that exist within our healthcare system one issue comes back to you again, and again, and again. And that is if we're going to fix this system we have to focus on quality. And if we're going to fix our system communities are where we have to do the work.

This is the best of times. This is the worst of times. The best of times because we have an increasing amassing of tools to begin to make the difference on quality and the work of the Institute of Medicine in this meeting here is going to continue that.

We have tools such as the Pursuing Perfection initiative by the Robert Wood Foundation to say that institutions can begin to improve the quality, not just one program at a time, but can create the culture across the whole institution, culture of quality, commitment to quality.

We have programs such as Rewarding Results where industry is saying, “We're going to purchase quality care and pay more for it.” And we've adopted various approaches to the chronic care model with initiatives such as improvement in diabetes where we're looking at not only just the issue of what

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**Crossing the Quality Chasm Summit:
Redesigning Care and Improving Health in Priority Areas
1/06/04**

9

goes on in the healthcare system, but also what's going on in the community in improving self care.

And then we have important, significant improvements within the national health information infrastructure. That agenda is being moved forward.

So it is the best of times. It is the worst of times. And perhaps one of the biggest indicators of the fact that now we're seeing some of the best of times are the people here in this room who are coming here today to begin this process of starting and developing a community based approach, coordination, and partnership to actually make a difference.

So this is not just a meeting about quality although that is probably why you all came. But I hope that you will see that your efforts today are not just about quality, but you are helping to transform healthcare in this nation, one of the most important tasks that you can be engaged in.

It is an honor, as part of the Robert Wood Johnson, our President, Risa Lavizzo-Mourey to be here, to be a sponsor to this important initiative, we look forward to your results, they will make a significant difference.

Thank you.

DR. REED TUCKSON: -- Thank you, Dr. Lumpkin. The quality chasm report advances many important axioms to guide transformation of the system.

Prior to coming to the summit we made a very great

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**Crossing the Quality Chasm Summit:
Redesigning Care and Improving Health in Priority Areas
1/06/04**

10

effort to refresh or further reform all of you regarding the concepts in that landmark report. You were mailed a copy of Crossing the Chasm and many of you participating in a Chasm 101 conference call session that was hosted by Dr. George Isham, whom I am pleased to acknowledge and thank today.

In your packet you should have a one-page summary of the Chasm report. We urge you to make frequent reference to those six aims, to the principles of redesign, and to the infrastructure changes that are necessary to realizing those six aims. We want you to be very specific about those recommendations. That's what we're here to talk about. We do need you to stay on point for the next two days. Please don't go wandering all off the reservation inventing many wonderful new things. We need you to stay on what we have come here to talk about. And I would appreciate your attentiveness to the fact that this is a Crossing the Quality Chasm summit. So if that's not the airplane you got on, this is your chance to disembark.

I don't know what you all are here for but...

As Dr. Fineberg alluded to, one of the recommendations of the Chasm committee was that the country should focus its quality improvement efforts on a critical set of clinical areas. As we have heard, these have been captured in a companion IOM study entitled Priority Areas for National Action. Based on these two reports, the charge to our

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**Crossing the Quality Chasm Summit:
Redesigning Care and Improving Health in Priority Areas
1/06/04**

11

committee was to further the implementation of these priority areas at both the local and national levels by focusing on five key conditions. To remind you, they are asthma, diabetes, depression, heart failure, and pain control in advanced cancer.

The IOM assembled a stellar committee to plan and guide this summit and oversee the follow up report that will document the discussions and the recommendations that we collectively achieve. I invite our committee members to please stand and be recognized for their dedication and hard work. Their names are printed in the brochure. And besides, I want you to know who these folks are as the day goes on. Committee would you despite your modesty please stand.

The IOM has also made available an extraordinary staff team to support this effort. Janet Corrigan, you are nothing short of spectacular and thank you so very much. And we are especially as a committee indebted to the fine and tireless work of Ann Greiner and Karen Adams. You all thank you so very, very much.

The committee's first decision was to develop three goals and objectives for the summit. They are in your brochure. And again I would urge you to focus on those for just a quick moment. Our purpose is first to stimulate and further local and national quality improvement efforts consistent with the IOM Crossing the Quality Chasm, focusing on the five priority areas that I just outlined.

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Number two - to describe measurable goals and appropriate strategies for improving care in the five targeted areas and identify possible performance measures that could be used to assess progress over the next three to five years. This is short term. This is immediate. This is not about pie in the sky. This is real time change.

And third to stimulate and make visible support of interrelationships and synergies between locally based efforts and resources at the national level. In fact, the subtitle for this meeting is a Focus on Communities.

The mechanism by which the committee chose to reach these goals was to invite by invitation only a group of leading but diverse communities from across the country and key national leaders who exhibit an extraordinary capacity to influence the quality of our nation's healthcare infrastructures. It is the committee's hope that through an active dialog and an active exchange between local community health system leaders and national leaders who are transforming healthcare more broadly, that we will help to inform and help to shape national policies that support action at the local level and help to sustain early adopters and foster the proliferation of more local innovators.

We ambitiously hope that we can stimulate the formation of alliances between our local community champions and the communities that are represented here and those that are not

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with our national leaders.

Our process for selecting the 15 communities that are present with us today out of the almost 90 that were initially identified is also detailed in your program book, along with a brief description of their quality efforts. And I would urge you to read that at your convenience.

Well, this is going to be a challenging two days. Especially if we are to succeed in our goal that this will not be just another meeting. The committee has worked very hard to structure an efficient and effective meeting that respects the time and the attention of such a distinguished group of participants.

We really do need the best of your creativity, the best of your experience, of your wisdom, of your judgment, of your patience, and probably from time to time we may expect and need your forgiveness.

We have tried to engineer this thing as tightly as we can. We were in a meeting last night and we were triple planning until late in the evening trying to imagine every scenario possible and one of our brilliant committee members finally just stood up, Cheryl, and said, "Listen. Enough already. We can't over engineer something like this. All you can do is do your best and then turn it loose."

So there will be some one of you I'm sure who will find their opportunity in the bathroom to like complain about

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**Crossing the Quality Chasm Summit:
Redesigning Care and Improving Health in Priority Areas
1/06/04**

14

something that we did do or didn't do. I don't know what.

Forgive us. Forgive us. Forgive us.

We are motivated by the reality of what is at stake. Whether people shall live or whether they shall prematurely die. And the quality of that survival is worth a meeting like this with all of the challenges that it takes to pull this off successfully.

Our nation has made considerable progress since 2001. We have all been learning as we go along. Learning as we lay the tracks and run the trains over the chasms in our healthcare system. But much more progress is needed and much more quickly.

You are invited here because you are smart, experienced, resourceful, committed, because you are special. We need the best of you.

What we learn here shall be made readily available to others so that they can benefit from our discussions and from our recommendations and strategy advice. In fact, we are indebted to the Kaisernetwork.org and the IOM for web casting this very plenary right at this moment. And you can also expect that the products of this discussion will be made available on the IOM website and in publication within, I am assured, three months of our adjournment. And we're going to work very, very hard to get this material to you in a timely way.

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Well, as you will see by looking at the agenda, and it starts on page six, we have an ambitious schedule before us. I will spend some time later going through this in a little more detail. But let me just warn you there is very little fudge room in this agenda. In fact, there is very little time to get from one room to another. And so there are lots of people here who will be holding signs and pointing directions and trying to get you from point A to point B.

Now we know you all know each other, or a lot of you and you want to spend a lot of time talking and catching up on how Christmas was and what a wonderful New Year's you had. That's all great. There is a networking part at the end of the day so I'm sure you can remember your stories until then. Today is not the time to spend a lot of time reminiscing. It's time to move from place to place in an organized way.

Let me also suggest that we are all very important people, at least you all are. I may not be but you all are. We have cell phones and calls to make and so forth and so on. This meeting is by invitation only. You are here specifically because of you. And so we would hope, and on behalf of the committee, it is my obligation and responsibility to fight like heck for this summit. I am here to advocate for the absolute best possible chance for this summit to succeed. And so I have to be kind of a curmudgeon. On behalf of our committee I've got to urge you please, please, especially you national

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champions, who I know have a tendency to wander, we need you in the meetings, in the rooms. We need you actively engaged.

So that's my commercial and if I see you doddling around in the hallway, I'm going to try my best to police you into one of the rooms. I had a, I rode here this morning with one of our local health system champions from Flint. And he really inspired me because he made it so clear to me that number one - they felt it was an honor to be invited to this meeting. And they were flattered by the invitation. And that was very important.

Number two - it was his expectation that he would not only contribute the best of their experience and their knowledge and their challenges as they actually implement these ideas or try to implement these ideas on the ground in real time. But he thought that he would, that their experience would be of importance and of benefit to the national champions that are here. And so we really do want to make this marriage. We have some pretty powerful national champions in the room, people who will determine the course of events. They need to hear and learn from what's happening at the local level as they create their national policy pronouncements and their strategies.

So this is a two way street. And we sincerely hope that you will give it your best.

Well, to move us forward exactly on time.

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We will begin the session by putting the patient front and center. We will have an extraordinary opportunity to hear a patient's story related by a family member, which highlights many of the gaps, dysfunctions, and mismatches in our current systems.

Three communities will then share how their efforts attempt to remedy such issues, where they have succeeded, and where they may have misstepped or have not been able to bust a barrier.

Following that we will have a presentation by Don Berwick and I will introduce him right before he speaks.

But to get us started let us turn the stage over to our Dr. Allen Daniels, a committee member and CEO of the Alliance for Behavioral Care who will introduce our speaker and moderate our consumer panel.

Thank you all very much.

(Pause)

DR. ALLEN DANIELS: -- Good morning. Oh good, we do have our screen back.

I am Allen Daniels and I am pleased to begin this next section of our summit today. As Reed mentioned we begin with a story. It's a story of pain, frustration, and most of all courage. Martha White-Cotton is here today to share with us her family's journey as they struggled to navigate the broken healthcare system for her son, Aaron who has major depression.

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She will passionately describe several of the system's failures that have prevented her son from receiving the best evidence based care we know is obtainable. Although her example is one of depression, her points transcend the chronic diseases and are really applicable for all of the four other clinical areas we are focusing on at this summit and beyond. And as Reed mentioned, this is a challenge to begin a process today that can go forward and carry us forward.

We begin with a story and we will follow with community stories from some of the selected communities who will be participating in this summit.

I'd like to introduce Martha White-Cotton. You will find her summary, her bio in your book. First and foremost she is a consumer family member and secondly, as Vice President and Chief Nurse Executive of the Carolinas Medical Center. Her biographical sketch I think outlines her professional activity. What she's going to talk about today is really her personal story. Martha would you come up and share your story with the group.

MARTHA WHITE-COTTON: -- As Allen said I am here today to testify to the struggle of a family with a disease called depression. I was actually thrilled when I heard that depression was one of the diseases chosen for this summit to focus on.

And I'll tell an interesting story. I have known

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**Crossing the Quality Chasm Summit:
Redesigning Care and Improving Health in Priority Areas
1/06/04**

19

Lillee Gelinas, who is part of the committee for many years professionally. And we were sitting at dinner one night and she was talking about the committee and the work and the planning for the summit. And she started talking about the diseases chosen. And I got excited and said, "You know, I'd like to say a few things to those people. I'd like to tell them what it's like." So, you know, be careful what you wish for because that's probably why I'm standing here today.

But I am hopeful that the lessons that my family and I have learned from this journey that I am about to share with you will shed some light on the system problems that need to be addressed, not only for depression, but for the other four diseases chosen for this summit.

Depression is described in the book by Andrew Solomon entitled The Noonday Demon: an Atlas of Depression as the mechanism of despair. It eclipses the capacity of an individual to give or receive affection. It destroys the ability to be peacefully alone with oneself. It destroys the ability of an individual to act on any motivation or desire. It is often associated with intense and paralyzing anxiety. Individuals with this disease are not depressed. They have depression. It is a disease. It is not a state of mind.

The note that I'm about to, if I'm successful with this tracking ball, show you on the screen (pause) marked the beginning of my family's journey with the disease of

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depression. It clearly did not mark the beginning of my son's journey or experience with this disease, only our full knowledge of the truth of it.

Our journey looking back really began in about 1983 when Aaron was 2_ years old. We had brought another sibling into his life, which is challenging for any first born I think. And one night we found Aaron in his room crying. And he was banging his head against the wall and he was saying over and over, "I am bad. I am bad."

We didn't know what to do. So we held him. And we rocked him. And we told him that we loved him. Calmed him down. And the next day we called our pediatrician who immediately referred us to a child psychologist.

We did make that appointment and he did a lengthy evaluation of Aaron and then talked with us for some time. And share with us that perhaps we were just overanxious as parents and that we were expecting too much from Aaron. He was a little bit intense. And that we needed to just back down, not ask too much of him. Not ask him to sit still in church. Not take him to restaurants late in the evening, etc. And so we tried to keep that advice in the forefront as we went through our lives.

But we also felt a responsibility to be good parents. We had to raise a citizen of a future community and of this nation. And we wanted to teach our children right from wrong.

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Throughout Aaron's life we were always aware of his incredible sensitivity and the depth of his emotion. I do not think we saw that as a weakness. Not ever. Progression through grade school and most of middle school was fine. His grades were always very good. Aaron tests consistently in the 99th percentile in every academic test he has ever taken, every standardized academic test. He excelled in sports. He made friends easily.

During Aaron's seventh grade year we began to see the first change in his grades. Although he continued to participate in sports and continued to enjoy those activities, toward the end of seventh grade he tried out for the baseball team. He did not make the baseball team. And a couple of days later he overheard the coach, who was also his geometry teacher, sitting with a group of his friends and sharing with these boys that Aaron was too fat and too slow to make his baseball team - strong words in the face of male adolescence.

We went to the principal about this incident. And she shared with us that we shouldn't do anything rash because this teacher was up for tenure and we would not want to mess that up for him.

Now if you question why we didn't take it further, we had another child in that school who was scheduled to have that teacher next year. There was a little danger for us to pursue that for our second child.

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The next year in eighth grade problems with grades and school behavior began in earnest. And some time during the late fall we decided to meet with Aaron's teachers. And they scheduled this meeting during the day. Aaron and I and his Dad attended, as well as the teachers. And they sat in a circle. Just try to envision this. We went around the room and every teacher told us what was wrong with our child, about his school behavior, about his school performance, about his personality, what was wrong with him. As we went around this room I watched Aaron. He had a big coat on. And I watched him just sort of sink into his chair, sort of slip into sadness. And I had this nagging feeling on that day that we were failing our child. That there was more to this story than we understood as parents.

But we still believed we had this responsibility to society to support the educational system, to try to partner with them. And so we supported his teachers and we worked on a weekly reporting system and we tried every model of reward and punishment conceivable. I challenge you there is not one thing you all can tell me that we didn't try.

It seemed apparent that this was adolescence and that we had to deal with it. Understand that we never questioned his academic ability. Again, as I said, his intelligence was consistently verified on standardized academic testing.

We've since learned the early signs of depression in

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adolescents do not look like those of adults. Often change in school performance is the first sign of mild or even major depression. This coupled with anxiety, increased sensitivity, and the onset of physical complaints; particularly headaches and stomach problems are hallmarks. Aaron experienced all of these symptoms.

Many teens at this time turn to experimentation with drugs and alcohol, not for rebellion, but for relief.

One Sunday afternoon we had a very intense exchange with Aaron over his inability to be truthful with us. And later when I went to his room to check on him I found the note that I showed you earlier on the screen. We called a friend that we knew from our church who referred us to a counselor. She was a wonderful family counselor. And she told us after meeting with us and spending some time with Aaron, that Aaron was at risk for suicide.

You cannot imagine or describe to anyone the impact of those words on a parent. And the belief that you, as a parent should have known, or better yet caused this pain.

Never during this time however did she suggest an evaluation by a psychiatrist, even though she knew, or had deemed Aaron to be suicidal. And it didn't occur to us at this time to go to our family physician; like it would intuitively I am assuming if you had a child with diabetes or asthma symptoms. It just didn't occur to us to make that call.

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Nor were we given or had an access to evidence based guidelines that would have helped us to recognize the danger signs and the next steps.

As many of you know, depression is a serious comorbidity for all of the other illnesses that we are focusing on at this summit, but it is often not formally diagnosed and the necessary resources are not accessed.

We spent six months in counselling with this counselor and we actually made tremendous progress as a family. And we naively believed that Aaron was back on track. We had this thing under control. And we stopped counseling for the summer.

And Aaron did seem to be on a high. He had been attending the Citadel's summer camp for boys, which is a military camp. And he finished as first honor graduate, which is, it's not a small feat in a military environment. They don't cut you any slack just because you're cute. You actually have to perform. And so he really seemed to be on a high at that time.

And through the next couple of years in high school it was sort of like a roller coaster, a pattern of ups and downs with grades and average adolescent issues. But we didn't sense strongly a return of the depression.

At this time we were well aware of a family history depression - Aaron's paternal grandfather and a niece on the same side of the family. Aaron was involved in a rigorous

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academic program called the International Baccalaureate. It is like undergraduate college work in high school. And it is very intense and is very stress producing. Aaron was also always involved in varsity sports, football, and wrestling. And those activities seemed to give him confidence where school did not.

During this time period we enrolled Aaron in Huntingdon Learning Center. And mainly just to see if we could improve his study skills or his approach to his work and perhaps that would improve his school performance. Understanding that college was on the horizon.

The owner of the learning center consistently met with parents of students that were enrolled. And she tactfully suggested to us, not knowing anything of Aaron's history, that he was perhaps experiencing depression. She was one of the few teachers we have encountered who had the insight to see this and the tact and the wisdom to approach us with it.

As I said before, all indicators were that it was not his ability so most of his teachers preferred to label him with laziness and rebellion.

In the spring of that year Aaron began to experience severe headaches. We visited our pediatrician who suspected a problem on his physical exam and referred us to a neuro ophthalmologist. We made that appointment. And she referred us for an emergency MRI to rule out a brain tumor. The MRI was negative. But for some reason Aaron told us later he didn't

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believe us. So he decided that he actually had a brain tumor and we just weren't telling him.

Now that would cause a great deal of anxiety for anyone. But particularly it did contribute to Aaron's anxiety.

As we were running between specialists, you've heard me name several there was no coordination of care among these specialists and with our pediatrician. And so Aaron's depression was never factored into the diagnostic equation for these headaches.

At the end of Aaron's junior year he did not receive his report card because of a parking fine. [Unintelligible] may have experienced that. I went to the high school and I paid the fine and was handed a report card with two failing grades. Aaron had never failed a class before.

Now understand that I had made numerous attempts during the school year to stay in contact with his teachers. I attended every parent/teacher meeting. I went to every session that was open. I met his teachers. I introduced myself. Ninety percent of the time when I tried to contact them I received no communication back.

The educational system spending more time during the day with my child than I was, failed me. They refused to partner with me. They did not return my calls and really just wanted to blame Aaron.

It is essential that the role of the educational system

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include reasonable awareness of the symptoms of depression in adolescents. And honor the necessity of engaging with parents on the solutions. I am aware of hallmark programs coordinating asthma care and asthma care plans into the school day for children. I am not aware of such programs for depression.

Again that summer we entered the counseling world. We tried a different counseling practice where the psychologist immediately replaced himself with a student. I am employed by an academic medical center and I understand an education mission. But my child in dire need of help was with an inexperienced trainee who had never counseled anyone before. He did not trust her and he did not form a relationship with her.

I will pause here to emphasize that families and patients must understand the critical nature of the relationship between the patient and the counselor or the patient and the physician. If this relationship is not strong and if it is not trusting, it is in vain. Based on Aaron's frustration and his insistence that we were wasting his time we stopped the counseling.

We tried our first medication that summer at the suggestion of a neurologist treating Aaron for his headaches. The medication made him physically ill. And if anything increased his lack of desire to interact with the world. He didn't even want to get out of bed.

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At the suggestion of the physician, the same physician we stopped the medication. We didn't start a different one. We've since learned the complexity of finding the right drug or combination of drugs for the treatment for each individual patient. And there is no simple answer. And while television direct to consumer advertising has raised awareness of depression, it's a little bit misleading in that this drug solves every problem you have.

So we didn't know what to do. Nobody was giving us any direction - not the counselors, not the neurologists, not the pediatrician. And once again care coordination across providers was absent. I emphasize this not only with regards to depression, but with regards to every disease we will be discussing at this summit.

We determined that summer that we needed to see a child psychiatrist. We came to this decision following a visit to a new pediatrician. Aaron had determined he needed to switch to a male pediatrician. And we took him in for an evaluation following our discovery that Aaron had been taking a sports performance enhancement drug given him by his high school football coach.

In my discussion of this issue with the new physician, Aaron's depression came up. He strongly encouraged us to seek psychiatric help immediately. It took us three months to get an appointment. And on the day of Aaron's appointment he was

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sick. So you guessed it. It took another three months to get another appointment.

One of the IOM six aims is timeliness. Six months is not an acceptable response to this disease or to any chronic illness.

At this time Aaron was rebelling against the depression. He insisted that he was fine and he was very recalcitrant when we finally did meet with the psychiatrist. Not, you know, there was nothing wrong with him. I am sure that it is not easy for a 17 year old male to admit to a perceived inadequacy, which is how Aaron saw the disease.

I shared with psychiatrist some of my observations and she had a discussion with Aaron and pointed out to him what depression is and what it is not. And made the decision that day to start him on medication.

The beginning of medication, as I said before, is an experiment in itself. The same medications or combinations thereof do not work for everyone. It took us a while but we finally hit upon a mix that seemed to work and began to work towards graduation.

I think it was on this day that our family began to fully own the diagnosis of depression. It was a landmark day in a 15 year odyssey. Timeliness as one of the six aims is also relative to timeliness of diagnosis.

The months leading up to graduation were very difficult

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because college acceptance had to be dealt with. Aaron wanted to play college football. Football recruitment is not a process for the faint of heart. It is a process whereby the coach is your very best friend until he signs the player just ahead of you on his list. And then he disappears from your life totally. Now that would be difficult for anyone. But for someone with depression that's not a pleasant process. Aaron was offered many opportunities at division two schools, but his heart was in division one.

One month before he had to make a decision about what college to attend, we applied to three more colleges - East Carolina, Clemson, and South Carolina. We made a trip to South Carolina and we fell in love with the school. Aaron attended a summer football camp there. Walked on. Made the football team. And played with Lou Holt. And attended the Outback Bowl during the Gamecocks' comeback season. He made the Dean's List first semester. We were on a roll. The medication was working and life was good.

We were easily misled. What we wanted was his dreams and our dreams to come true. Now we understand more about depression and we know that there is no cure. It is your life and it takes hold of you when you least expect it and when you are least prepared. It takes hold of you in places where you have no support system such as an all male college dorm in South Carolina.

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Second semester Aaron pledged a fraternity against our reservations but understand he had just made the Dean's List. He was happy. Things seemed to be going his way. And we saw, I think, what we wanted to see. Several months later he was asked to leave the fraternity for getting into a fight with an upperclassman. He became detached, very difficult to contact. We didn't travel to South Carolina to check on him. I don't know why we did not. We wanted to believe that he was okay when he said he was okay.

He told us that he had dropped a class and he told us he saw the football team doctor and that they had changed his medication. And we were actually pleased that he had admitted that he had a problem and had sought help. And we didn't go to South Carolina to check on him. We didn't call his primary psychiatrist. We didn't understand the importance of that.

At the end of the semester Aaron seemed a little reluctant to come home and actually disappeared for a couple of days. We could not contact him, couldn't find him. Again we didn't travel to South Carolina. And I don't know why. Finally, he did call. We were able to make contact with him. And he came home the next day. And he just said he'd been tired, catching up on sleep and everything was fine. His grades were fine. Everything was fine.

When someone with depression tells you everything is fine it probably isn't.

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The grade report came - five F's. He had failed every class, unbelievable our lack of understanding of the scope and the breadth of this disease.

Later that summer in the midst of a combination of counseling and medication Aaron shared with us that during that spring semester he had hit bottom. He had not left his bed for three weeks. By the time he was able to come to the surface again too late to save the semester although I am sure he tried. We will never know what went on during those three weeks in Columbia, South Carolina. We are only thankful that he did not have the strength or the solitude to take his own life.

We later determined, later on as this process went on, that the team doctor had changed his medication dose significantly without consulting his primary psychiatrist. The medication alone, according to our psychiatrist, could have caused his breakdown. I remind you again of the continuing need for the emphasis on patient safety and care coordination. Neither were taken into consideration by this team physician caring for Aaron.

Following an intense summer of counseling and medication Aaron's counselor decided we should give him another chance at South Carolina. That was the thing to do. Give him another chance. We made the agreement that he would see a counselor down there. We made a relationship with the

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counselor. We talked to her on the phone. Aaron signed an agreement that she could contact us if he missed appointments or if she sensed a change in his behavior or state of mind.

We made that initial contact with her and never heard from her again through the semester. So, of course, we assumed everything was fine.

At Christmas Aaron came home, told us he thought he'd made A's and C's. Everything was fine. The grade report came - four F's and one withdrawal. I honestly believe he thought he had pulled it off in the end but he didn't.

And in depression you will find that if the truth is painful the patient will often invent another truth that's much more pleasant to live with. But ultimately, of course, the pain is much worse.

And several months later I received a bill from the psychologist and I determined from her bill that Aaron that only made it to that one appointment. She did not honor her professional pact with us. And she did not appear to have Aaron's safety or well being at heart.

The last few years have been up and down. Some semesters were pretty good and others had many failures. As parents we have struggled with Aaron's inability to be honest with us about himself and how he's feeling and his disease. As parents, because of his age, we cannot know unless he tells us. Understand that we are shut out of his therapy. We are shut

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out of his education, and at times his world. Alcohol is a challenge at times primarily because of the mood altering effect. Understand that you have an opportunity to feel good and feel confident, only for a little while.

At the age of 22, at 22 Aaron is now, he is a little more honest with himself about his disease. I took him out to dinner in preparation for this testimony. I did this with his permission. And I asked him what he would want me to tell you. And he said to tell you that depression is not a disease you catch from having unprotected sex. You can't catch it. And you can't cure it. It is what it is.

He must learn to navigate his life in the context of his disease. He must learn to know himself, the signs of breakdown, the signs of medication failure. And he must know when to seek help. Patient self-management is critical to depression as it is for each of the clinical areas that we are focusing on.

The challenges for us beyond our personal heartache over the seeming unfairness for our child have been with every system imaginable. The education system must be addressed and the increasing incidence of adolescent depression. You often read a quote from a family whose child has committed suicide and they say, "We had no idea anything was wrong." I believe that is because we don't know what the signs are so we mistake them for rebellion or for hormones and we think we can solve

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them with discipline and reward.

The systems that surround our children must be designed to assist us in this endeavor. Teachers are in a unique relationship with our children and at a minimum they should be required to communicate with parents so that we have all of the pieces of the puzzle and we can track the early signs of failure.

The healthcare system failed us. Our pediatricians, neurologists, and counselors all made suggestions and all made attempts but it was all soft and it was not directed to a solution. It was sort of a guessing game for all of us.

And healthcare system, let's name this disease and make strong, confident, well thought documented, well supported treatment decisions. Patients and their families need to understand and demand the best evidence based care. We've since read over and over that the best approach to adolescent depression is a combination of medication and counselling but no one told us that. We had to figure it out by trial and error. No one told us about the importance of that relationship between a counselor and the patient. And no counselor, whether it be through ignorance or greed, was willing to tell us when they thought we should try someone else.

Given what I know now, if you believe that someone near you is suffering from depression, get help. If you don't

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believe the first attempt is effective don't be patient. Don't mess around. Ask everyone. Read everything. Be aggressive. Do everything it takes to find someone to help you, the right person. And always listen to your instinct about how your loved one is feeling or responding to his treatment.

It is inconceivable to me that a child who shows up in the doctor's office with urinary frequency and insatiable thirst would not be assessed and then treated for diabetes. It should also be inconceivable that the hallmark signs of depression should not be recognized and appropriate assessment formed and an intentional treatment regime be initiated. And never should a physician change a medication regime for depression without consulting the primary treating physician. No more than an oncologist would change a chemotherapy protocol of a patient that was not in his care.

Last spring Aaron went to an urgent care center seeking treatment for headaches. And the physician there, with no consultation with his primary care providers, prescribed for him a migraine medication. Based on his previous experiences and much coaching from his mother, he didn't take the drug. And he was diagnosed two days later with a sinus infection.

The payers failed us in our ability to sustain one of the IOM ten rules, a continuous healing relationship. One hundred percent of Aaron's initial counselling was paid for out of pocket. Prevention of a major breakdown just did not figure

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into the benefits of our health plan.

I was told a year or so ago that we would want to change psychiatrists because our health plan no longer covered her services. I told the person on the phone who identified themselves as a care coordinator that they clearly did not understand the intricacies of the relationship between a patient and his counselor and his psychiatrist.

If we are to focus on continuous healing relationships, how do we reconcile that with changes in our benefit plan? If we had not been financially able to define our treatment options we may not have had any options. In any of the chronic illnesses, which are the focus of this summit, the doctor/patient relationship is an essential component of the good outcome.

This November Aaron reported to his physician that the generic form of BuSpar did not seem as effective as brand; in fact it seemed to have no effect. And so, you know note self-management, what have we been asking him to do. She wrote his new prescription for brand. And we received a call a few weeks later from our insurance carrier that they would only cover generic or we could pay \$450 for a three months supply of brand BuSpar.

It seems that our treatment is defined again, not by its efficacy, but by the parameters of our health plan. I don't want to think what this would be like with no health

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insurance at all. And there is a mail order process that many of our insurance plans dictate for receiving medication. The medications do not come on time. And despite my multiple phone calls to the drug plan coordinators, they don't seem to understand that you can't just skip a week of medication while you're waiting for that to come in the mail. I've been on the phone in tears multiple times on this issue to no avail.

Despite the fact that respite from the stress of college may benefit Aaron, he stay enrolled so that he can stay on our insurance. We understand that he may likely be uninsurable if he has a lapse in coverage. Then what would happen?

Then he would become medically indigent and be forced to enter the system through an entirely different route switching from the private sector to the public sector. No doubt starting over at square one with new doctors, new medications, new challenges - none of which may be prevention focused.

I cannot overemphasize the necessity of integration between all care providers. To this day all messages are carried through me or through Aaron between his psychiatrist and his primary care physician. They have never considered to my knowledge having a conversation around a coordinated treatment plan. And to extend these conversations to school counselors, teachers, principals that would be revolutionary in

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the treatment of this disease.

I will not say that society failed us but we were reluctant to turn to our natural sources of support. Society as a whole does not understand depression. We often hear our friends and family say things like, "Nothing is wrong with you except you're depressed." Well! "And are you still having to take that medication?" Or, "What is he upset about?" And because we don't fully understand this illness, we're ill equipped to explain it to anyone else.

In the past we tried to respect Aaron's privacy by not discussing it openly. But I contend that if he was diagnosed with cancer we would seek support from everyone, friends, family, and they would flock to our side. But a diagnosis of depression leaves people not knowing what to do or what to say. And our pride often stops us from asking for help when we need it the most.

In truth, when we finally found the courage to confide in our family and our friends they came to our rescue. They love us and they love Aaron. And we are strengthened by their love.

I would be remiss in not saying that there were a few teachers who reached out to Aaron, took the time to know him as a person, who encouraged him and saw the best in him. And we will be forever grateful to those teachers. They've made a tremendous difference in the life of our child.

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In preparation for this testimony I asked my family what they wanted me to convey to you. What struck them the most about this journey. My daughter shared with me that she hated the years of tension and sadness over Aaron and the problems associated with the depression. She could not separate herself from it. And she could not fix it. She loves her brother. But she resents that this disease has consumed us as a family.

As parents we have struggled with our ignorance and our helplessness, if we had only known then what we know now. As a healthcare professional, I have always been the way finder through the healthcare system. I could find the best doctors, the best treatments, answer all the questions but not this time. I felt like I had failed my own child where I helped so many others.

Aaron's father agonizes over his approach to Aaron doing all of the wrong things but meaning to do all of the right things, the wasted years of reward and discipline when we should have been studying this disease and aggressively seeking the right treatment. Again, we did not know.

And finally Aaron - Aaron described the depression for me. He said it's like being in a dark cave. You can't see. And you can't find your way out. Periodically you think you've found a way out but it's not there. And finally you give up.

The IOM report, Crossing the Quality Chasm, says

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patient experiences should be the fundamental source of the definition of quality. If that is so, we have a long way to go with the patient's experience of depression. And probably for the other conditions that we are focusing on here today.

As I reflect on the IOM ten rules I've strived to emphasize the gaps that are keeping us from achieving the healthcare system that is envisioned in this report. We are getting there but to this day no one has ever sat down with us as a family and discussed this disease, the symptoms, its management, its future in our lives.

I recently had a friend who was diagnosed with breast cancer. She got a first opinion. She got a second opinion. She attended a multidisciplinary cancer clinic where the best evidence was laid before her so that she could chose her options. How I long for that opportunity.

There are five very different diseases chosen to focus on today. It strikes me that there are many parallel issues that we face. I have heard adolescent depression compared to juvenile diabetes, which is more severe than adult onset diabetes. It is a disease that requires constant monitoring and the administration of medications to keep the patient alive and functioning. It is not something you do casually. It is a life threatening disease, as is depression.

In our experience in the management and treatment of depression the following things have a recognizable effect.

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Leaning on those who love you, consistently taking your medication forever, exercise, regulating eating and sleeping to avoid extremes, simplifying life to lift stress as much as possible, and learning to be honest with yourself and others.

Overuse of ineffective care in the treatment of depression exists as well as the under use of effective care as I've tried to illustrate here today.

But perhaps that is largely because of the lack of education about this disease and its treatment options.

Perhaps it is because of a lack of information and experience with the medications, especially their use in children. And that is a whole another issue, an entirely separate challenge, pursuing extensive drug trials in children before we find out that Paxil may contribute to suicide in adolescents with depression.

Perhaps it is just because it is an unpleasant disease that Americans prefer to explain away with motivation and self help. They do not understand that the risk of death from depression is high, as it is for diabetes and congestive heart failure.

I wish that every one of you here could know my son. He is outgoing. He is engaging. He is intelligent. He is wonderfully sensitive and deeply caring. Loves sports, history, and his family. He forms long lasting friendships and he is fiercely loyal to his friends. He is saddened by his

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failures but he is optimistic about his future. I do not want my description of this disease or our experience to define him.

I've changed my approach to dealing with depression. And I now talk about this experience and this disease to anyone who will listen, which is probably what got me here today. I believe that the only way that I can make any sense of it is to try to assist others on their journey. Perhaps they can benefit from our experience.

It is why I stand here today to validate the work of this committee - to get us over the chasm between what is actual to what is possible, to continue to pursue this system's approach to addressing these diseases. I do not want to waste this journey.

DR. ALLEN DANIELS: -- Thank you, Martha for sharing really a remarkable journey with us. Your courage to persist through this and your courage to share this with us is absolutely remarkable and we really appreciate it.

We're now going to move on to the community panel's portion of our morning. We have three communities with us - the Mid America Coalition Healthcare Community Initiative on Depression, the Greater Flint Health Coalition, and the Children's Mercy Hospital Kansas City Asthma Coalition. A description of each of these coalitions and community initiatives is in your brochure. I encourage you to read it as we go through this so you can familiarize yourself with it. `

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We've asked that they present each for about 15 minutes. They'll be presenting from the table where they sit. And reflecting back to the crosscutting themes that Martha so fervently brought to our attention, they'll be sharing with us their strategies, their stories, the lessons they've learned in striving to implement these crosscutting systems and system level interventions to provide high quality, patient centered care.

I emphasize once again that the community examples you will hear will apply to all clinical areas being featured today. The communities featured on this panel represent multiple chronic conditions including depression. They represent a broad and different group of stakeholders, different levels of professionals will be presenting from each of the coalitions.

Now I introduce to you the first community representative, Bill Bruning from the Mid America Coalition on Healthcare Community Initiative on Depression. And again his bio sketch is in your brochure. Thank you, Bill.

WILLIAM BRUNING: -- The Community Initiative on Depression that we began in 1998 started with a focus on the financial cost of depression but very quickly, I think, evolved into the very real and human systems issues raised by Ms. White-Cotton. The Mid America Coalition on Healthcare is an employer coalition seeking to improve the health and wellness

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of our employees and of the community and to contain healthcare costs. We're like probably 100 other coalitions in the country in that regard with one difference. We have 25 years history in absolute collaboration. We bring everyone together at the table and we focus only on areas where everyone's interests overlap or in the current economic environment, where people get equally gored.

We have determined that we cannot solve the problems of the healthcare system with government mandates or regulations or corporate fiat, but rather by getting all the components together to address the issues.

If you will indulge me, I want to talk about five or six projects we've done in the past that reflect what happens if our communities collaborate. So essentially this first part is a commercial to all of you - consider collaboration.

We've determined, for instance, that half of physician health claims that are rejected by health plans on first pass are rejected because they have an incorrect patient ID number. We now have all the health plans in the region redesigning and simplifying their patient ID card, a simple, geeky thing to do.

All the health plans have signed a HDIS chart review protocol that we designed. It streamlines and simplifies this huge hassle in the lives of physicians. NCQA incidentally ought to adopt this. It's a simple no-brainer and it makes a difference.

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We have physicians in Kansas City now conceding in writing that their claims, when they're rejected by health plans, are not rejected because of a fault of the health plans, but because of physician errors in their practice. I don't know anybody else who's got physicians admitting that.

We have all the hospital regions voluntarily last September reporting their quality numbers, their CMS data in the most effective attempt apparently in the country to do that. Prior to that we had a fully collaborative leapfrog (misspelled?) project with six months of dialog between the health plans, employers, hospitals, and physicians.

And finally we have employers who believe that they win in the end if money is pulled out of systems inefficiencies and complexities, unnecessary duplications. They're not looking for a direct one to one. They're focused on changing the system.

With that background, let me talk about the community initiative on depression. It began as an attempt by eight employers to figure out what our employees are doing to themselves. We conducted a BIRFA (misspelled?) survey. We identified seven issues where we didn't look good in Kansas City and that perhaps we could address using what we call a public health model recognizing we can't just work in the worksite; we also have to work in the community and in the clinical environment.

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We identified seven issues. The health plans at that point told us very compellingly why we needed to tackle depression, which we did. (Unintelligible) 15 employers, 140,000 impacted lives, many of these employers are national employers. You'll recognize American Century, Cerner, Hallmark, Sprint, and Yellow Freight. We are now in the third phase of this initiative and I think we have already had a significant impact. Our employers understand the human and the financial costs of depression and their role in the design of healthcare benefits to impacting that disease. And they're prepared, and in fact are opening their worksites to national researchers and their healthcare data as well.

The health plans are addressing their role in creating very real barriers to the diagnosis and treatment of this disease and using their remarkable expertise in educating providers and members.

The providers are becoming better educated on the disease. Less stigmatized. And they are being urged by employers, the ultimate payors to address this disease.

We hope in the end to have a significant impact on the community as well - educating community and focusing on the purported stigma around depression.

We'll culminate in actually a depression screening day in October of this year with hopefully a community wide screening for depression.

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I'm going to focus on four themes that Ms. White-Cotton has addressed - financial and business case for addressing a disease, patient centeredness, evidence based care, and care coordination.

First is the financial and business case that we are trying to make for addressing a disease. Ms. Cotton said very baldly the payors failed us. Our treatment was defined not by its efficacy, but by the parameters of our health plan.

With that in mind we, one of our first projects was the depression and coding reimbursement project. We recognized, it's well recognized that depression is widespread in primary care. Roughly 50% has been suggested of people who come in to primary care physicians' office have multiple symptoms of depression but less than 1% of the claims health plans get reflect that diagnosis. Physicians are reluctant to treat it in part out of a lack of knowledge, in part out of a real stigma, and an appropriate stigma on their part, and frankly in the end because they don't feel they're going to get paid to do it.

We had one office manager who had the nerve to say it and several then repeated it. They have said more than once, "Don't diagnose depression doctor, we will not get paid for it."

We had another oncology officer manager say, and I'm sorry this is graphic, but she said, "It is easier for us to

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get paid for treating bleeding of the wrist than it is for depression.”

With this in mind, we brought together the health plans, the physicians, and the medical office managers. And I must tell you this last group is a huge partner for us. These are the people who are impacting the healthcare delivery system where the rubber meets the road.

Early in this process when we had a joint meeting we had a couple of physician office managers say flatly to the plans, “Do you or do you not want us to treat depression?” It was just that simple. The answer was, “Yeah, I think so. I was surprised they did. They couldn’t say yes. But that was at least a positive sign.

We then studied each health plan’s division three logic for mental health claims and clearly the answer was yes. And yet the reimbursement patterns suggest the answer is very frankly for the most part, and there are some exceptions, but for the most part, “Well, no. We really don’t want to pay you to treat depression.”

We’re going to run some test claims. We’re going to find out what’s going on when a physician submits a claim. I think we’re going to find it is the human component that is popping these claims out.

A couple of other things we’re doing in terms of the business case. We are in a dialog with CMS on reimbursement

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issues. They are, by this disparity, between 50% and 80% reimbursements are significantly clouding the issue. We're also in dialog with one of our partners in this project, the American Psychiatric Association, simply to redefine depression, perhaps as a serotonin deficiency. I mean if it goes from a mental health definition to a physical definition that may be the way this particular disease's reimbursements problems are addressed.

Patient centeredness - the experience of the patient and the families - Ms. White-Cotton said, "Our lack of understanding of the scope and breadth of this disease is unbelievable. No one ever sat down and discussed it with us."

The first thing we did, almost the first thing we did in designing this project was to design and conduct an employee attitudinal survey. We used pharmaceutical expertise and sampling and we brought them together with local experts in mental health and we designed a survey. Eight employers passed out to 39,000 employees. And we learnt some very interesting things; things that have informed most of our projects since then.

We learned that there's pretty good awareness of the disease but yet actual knowledge is limited in several areas. We learned that there may well be less stigma than we all presumed people to have today and that there's a real openness to being treated for the disease. We learned that people are

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inclined to seek help from their family physician. They look to self-help techniques as Ms. White-Cotton noted. And they also turn strongly, a remarkable percentage, to their religious beliefs to address this. And interestingly, frustratingly, there was a perception that there were virtually no resources available to them in the workplace, notwithstanding the fact that all eight employers essentially had mental health parity. As I say, this was the first thing we did in our project and it has informed most of our initiative since then.

The other area - evidence based care, clinician, and patient education. Ms. White-Cotton noted, "We have struggled with our ignorance and helplessness. We need access to evidence based guidelines." In this regard in Kansas City we were lucky to have an ongoing UAW Ford project, the Kansas City Quality Improvement Consortium who is working on best practices. They agreed to add to their list of diseases the disease of depression. And we have now developed a community consensus around how physicians will address this disease and the health plans have all adopted it.

We are going to use this, these best practices now, in a variety of projects. Most interestingly, we are developing a project to provide information to every employee who is diagnosed with depression, or perhaps more tellingly, who is prescribed an SSRI. We are going to advise them of the best practices. The level of care they ought to expect from their

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physician. We're also going to advise the physician that we're telling their patients this.

We expect a fair amount of pushback but some early studies by Blue Cross in Kansas City suggest it may be more accepted than we had anticipated.

Another thing we've done coming out of the employer attitudinal survey was create an Intranet module within each workplace of the three things that we've determined that people need to know about depression. First is the facts, the real facts on the disease. This will be a link out of the Intranet site into a site that the American Psychiatric Association has developed fairly much like their workplace stress post 9/11 site, if any of you have seen that.

The second component is community resources, not only for the employee but also for the dependents and also for Mom who is living with them. We're going to link out of each employment site into the Healthy Kansas City website that we've been involved in helping to create which will give all the resources within the community.

And finally, the third component, we're going to address the benefits that they actually do have through their employment and that will be a link within the Intranet site to the benefits section of that employer's site.

And then finally in terms of education, Fleischmann-Hilliard, a national public relations firm has put together a

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model community rollout of this disease. We are using Pharms, a pharmaceutical company direct to consumer expertise. I've heard Ms. White-Cotton refer to that as a travesty, DTC but the fact is they know how to get to people. And we're going to try to figure out how to fully rollout this disease to the community and then coordinate it, culminate it, as I said, in a community event in October.

The last component that Ms. White-Cotton talked about that is completely germane to what we're doing is care coordination, particularly across multiple providers. She said flatly that there was no coordination of care among specialists and pediatricians. We're working on that through the guidelines we talked about, through the definition of PCP broadly to include obstetrics, and gynecologists, oncologists, endocrinologists.

We're looking at a program to do research in treating depression in cardiology and oncology and in our obstetrics and gynecology office. All three have volunteered to do this. And we're going to focus on can they treat it but can they also coordinate back to the primary care physician and on to the mental health professional.

And finally, one of our participating employers, Blue Cross/Blue Shield of Kansas City has put together a depression management toolkit, which includes a continuity and coordination of care form. And they are having meet and greets

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between primary care physicians and mental health specialists.

I hope we have recognized most of the issues Ms. White-Cotton so dramatically put in front of us. At the end, if we have we're going to document the project in a way hopefully that it can be duplicated in other communities around depression. We're going to be looking at the model also for obesity and perhaps diabetes, or some other healthcare issue.

Thank you very much.

DR. ALLEN DANIELS: -- Thank you, Bill.

Our next speaker will be Henry Gaines from the Greater Flint Health Coalition. Again, his bio sketch is available in your brochure. And with that let me turn it over to Henry.

HENRY GAINES: -- Thank you, Mr. Daniels for the introduction and thank you Ms. White-Cotton for openly and honestly sharing your son's story with us. Your testimony not only brings a personal face to the destructive effects of depression, but also highlights how our nation's system of healthcare can sometimes work well and at other times fail us completely. The fact that your son in at least one point during the course of his illness was receiving the right mix of medication at the right dosing schedule demonstrates that we often have the knowledge to adequately treat disease. What was missing in your son's case however was the ability to maintain your son's wellness.

You eloquently described some of the barriers that many

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**Crossing the Quality Chasm Summit:
Redesigning Care and Improving Health in Priority Areas
1/06/04**

55

Americans face when assessing healthcare - inadequate coordination of the patient's care, difficulty in meeting the cost of lifesaving medication, clinical environments that are not patient centered. Thank you for so honestly sharing how we, the healthcare system let you down and giving us the opportunity to learn from your experience so we can make improvements for the future.

As stated by Mr. Daniels, I have been invited to speak to you this morning because of the cutting edge activities in Flint, Michigan, which have been significantly improving the quality of our community's healthcare. To help the mechanism through which we have brought about a positive change I will refer to the business plan of the Greater Flint Health Coalition.

The Greater Flint Coalition is a non profit, 501c3 organization whose mission is improve the health status of Genesee County residents and to improve the quality and cost effectiveness of the County's healthcare delivery system.

Approximately half a million people live in Genesee County, approximately 75% white, 20% African American, nearly a quarter of whom live in the city of Flint, which is approximately 54% African American and 42% white.

General Motors, which was founded in Genesee County in 1908, is the county's primary employer and the county continues to be heavily influenced by both GM and the United Auto

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Workers.

The Greater Flint Health Coalition is both a community institutional partnership and a multifaceted collaboration with the Board of Directors that broadly reflects the community. WE have sectors of government, hospital, labor, business, insurers, physicians, and the educational system, and consumers and faith based organizations.

It is important to note that while General Motors and the United Automobile Workers are an important part of the coalition, as well as the Greater Flint community, they are just two of many partners. The Greater Flint Health Coalition is not a purchaser coalition.

As noted on the business plan, and I was going to try to use a pointer but it's kind of hard to do it over my head here so you'll just have to kind of look up there, this will be available to you later on so that you can actually get a little closer.

As noted on the business plan, you can see that the coalition truly encompasses a diverse representation of the community's healthcare leadership and if you notice the CEO from the county's three hospitals' executive leadership. of the county's primary insurers, the Medical Society, Osteopathic Association, the Public Health and both business and labor are all part of this organization.

Coming together this leadership must not be

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underestimated despite competing and sometimes conflicting individual organizational interests, these key healthcare stakeholders have committed to work in partnership on a wide array of healthcare issues that affect the Greater Flint community. Without a doubt the relationships between coalition members have grown beyond that of a simple partnership to one that is symbiotic. The coalition's members depend on each other, realizing that through working together greater things can happen than if isolated, and working alone. But admittedly a relatively small microcosm in the arena of our nation's healthcare system, we demonstrate that a viable working model how both private and public sectors can join together to accomplish great things.

I'm just going to highlight just a couple of areas and then we've got to move on.

There's a sector up there called Quality Evidence Based Medicine and under that sector we have had a couple of projects that we are working on. One is Back Pain Management Task Force. We've been working for the past year to put together a set of guidelines that will be rolled out to the entire community on how to treat and deal with people who have back pain. And that will be rolled out to the community in the spring of this year.

One of the issues of that, you know, it is easy to sit here and talk about the successes that we've had, but one of

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the problems we had in putting together this particular project was that the surgeons had a distinct disagreement in how people should be treated with back pain as to the other physicians involved as you might imagine. And so it took a great amount of work to try to get the two groups to reconcile their differences at which we failed. However, we also took the time to try to work out a compromise that would allow us to move forward with the project at which we did succeed. So it's not always, is you're going to win all of your outcomes but you do have to keep working at it to achieve some.

Our Heart Failure Task Force, of which Dr. DeFranco will be presenting later on, is another quality project that we're working on. And I'm not going to spend a great deal of time to talk about it except to say that there is a sub study talking about coordination of care that's a part of the Heart Failure Task Force that's measuring the prevalence of heart failure in alcohol use and its effect on comorbidity.

On our Cost and Resource Planning Committee, this is where most of the decisions for the task force that we undertake are made. They are supported by a Data Review Subcommittee who reviews all of the medical data within our community to help point us in appropriate directions so that whatever we undertake is data driven.

And then our Prompt Payment Task Force, which is one that is very important to the doctors and the hospitals deals

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with the issues of getting paid for the services you provide.

I'm going to move on and talk about some other things a little later on in this process. The Institute of Medicine's Quality Chasm report asserts that patients in the community should be the fundamental source of definitional quality. Realizing this principle however can be a rather daunting task, what are the alternatives?

As the Quality Chasm report highlights and as Ms. White-Cotton related in her personal testimony, one consequence is that pervasive (unintelligible) in the quality of healthcare remains stagnant and relatively unchanged. In nearly any other industry, as I can attest to as a member of the automotive industry, stagnation and insensitivity to the needs of customers can result in a corporate disaster. Customers stop buying your product, leaving you and your customer (unintelligible) product behind.

In healthcare however, people's choice is limited and the option to seek care from a competitor is often impractical or wholly unrealizable. Choice is limited by insurance coverage and proximity to providers. It is limited by demands on providers who often have only five minutes to assess and treat a patient. It is limited by the demands of the capitalist model of healthcare, which can made corporate profits a tempting lure away from the primary interests of the patient. It is limited by a political environment that cries

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foul about the rising cost of care but then baulks under the pressure from special interests when it comes to making necessary healthcare reform.

Undoubtedly, the obstacles we have to overcome are large but they are not insurmountable.

Through the Greater Flint Health Coalition we have several continuous quality improvement activities that addresses the gaps in healthcare quality.

The purpose of Friendly Access, and that's one of them, is to change the culture of maternal and child healthcare in Genesee County, to improve the health of mothers, infants, and children. Friendly Access is designed to link maternal and child health programs in an effort to increase the access, satisfaction, and utilization of the prenatal and the pediatric care system.

Friendly Access provides a path to change that leads to improved health for mothers, infants, and young children. This path in part is built upon the customer service model developed by the Disney Institute. It is nationally renowned for its training in the area of customer satisfaction, service delivery, and performance excellence. The Disney Institute assists healthcare leaders, clinicians, and frontline providers to learn the principles of customer service and develop a strategy to put them into action.

Understanding who your customers are in order to better

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service them is one of those principles. Anticipate the needs, wants, stereotypes, and emotions of your customers or patients in order to exceed their expectations. Improve the policies, tasks, and procedures within organizations to promote the delivery of quality service to customers and patients. To motivate employees to actively deliver consistent quality service, prioritize service standards to promote the delivery of quality service and establish a more efficient process for delivering quality to your patients.

Another activity of the Greater Flint Health Coalition that helps orientate healthcare professionals is to tune into the needs of customers is the Undoing Racism Workshop. The Undoing Racism Workshop is a paradigm shifting two and a half day workshop in personal and community empowerment. These workshops, using a model for social transformation through community organization and leadership development are designed to help participants understand institutional racism and develop their own analysis of history, culture, power, and relationships.

While not the direct focus of the summit, it is worth noting that the Institute of Medicine has a comprehensive report addressing racially linked health disparities titled Unequal Treatment Confronting the Racial and Ethnic Disparities in Healthcare. To date about 400 people have attended these classes.

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While these are only two of the 16 activities outlined in the Greater Flint Healthcare Coalition's business plan, to demonstrate our commitment to working with the citizens of Genesee County in defining and improving patient centered care later in the summit Dr. DeFranco and colleagues will be describing in detail a systems change approach to quality via the guidelines applied to practice in the heart failure project, a project building off our success with a similar activity addressing acute myocardial infarction.

In closing, I'd like to leave you with two questions that I often hear when I walk about in my community. One is, "How many more times will we be the subject of someone's master's or doctor's thesis? How many more times will we be studied, prodded, and probed? How many more times will we be used to gather grant money for others to use and yet our health outcomes never change?"

And then the second question is, "As we sit here today to discuss quality and all the ramifications of it and all that it can bring, how is it that we're not talking about the 44 million people who are uninsured? Are we simply talking about quality for those who have access to the system or have we forgotten that those who don't have appropriate access are looking for quality care too?"

Thank you and thank you Mrs. White-Cotton.

DR. ALLEN DANIELS: Thank you, Henry. Very nice job.

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Lastly I'd like to introduce Jay Portnoy from the Children's Mercy Hospital, Kansas City Asthma Coalition, and again his biography information is your packet.

DR. JAY PORTNOY: Great. Thank you. I'd like to thank the organizers of the meeting for inviting me to this meeting, to be invited. I'd also like to thank you for the honor of allowing me to participate in this plenary session. I'd like to start out by making a confession, though, and that is that I'm not really a doctor. Sure, I have the credentials, but the reality is I'm a patient who became a doctor in order to create change from within the system. That's the way I think of myself. Now, I come from the Kansas City area. Kansas City is in the geographic center of this country. It's a community of one and a half million people. In that community we have 80,000 people with asthma, 23,500 of whom are children. I'm a pediatrician. I work at the children's hospital. At Children's Mercy Hospital asthma is the second most common reason why people are admitted to the hospital, the most common being premature birth. It's also the second most common reason people go to the emergency room - the first being the common cold. So it's an extremely common problem and that's why I've become so interested in it. Now, I'd like to introduce you to a patient of mine. I saw Chris - Chris was 14 months old when I first met him, and he presented with a history of eight hospitalizations and 15 visits to the emergency room in his

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short 14 months of life. That's outrageous. He was diagnosed with bronchiolitis, with pneumonia, tracheomalacia, and, oh, a panicky mother. After all, the doctors couldn't believe that a child could have that many hospitalizations and emergency visits unless something was wrong with the mom. So blame the patient, right? His treatment had included antibiotics, humidified oxygen. The bottom line is none of the treatments worked. Now, we're talking about a variety of themes at this meeting. We've got five themes - patient centeredness, evidence-based care, health management, care coordination, and finance business case. I would like to propose to you that if we place as the axiom that the patient is the center of control all of these themes collapse down into a single central theme. They are all manifestations of one single theme. Like Euclidian geometry, you start with a single axiom and an entire system of mathematics springs forward. If we start with the axiom that the patient is the source of control, all of these themes collapse down and are all manifestations of one thing. Now, we needed to realize that all of the different people - parts of the healthcare system have their own goals. The patients have their goals. Chris' mom wanted Chris to get better. But the Microsystems, the providers, had their own goals, which weren't necessarily the same as Chris' goals. The organizational levels, the health plans, they had their own goals, and the environment national organization context had

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their goals. All of these groups had different goals so of course they were moving in different directions. And what the Crossing the Quality Chasm report has emphasized is that we need to redirect all of our goals so that we're moving towards what the patient's goals are. That is the bottom line. Now, the healthcare system defines these goals in all of these different ways. We would never accept that kind of system from another context. And I like to use the analogy of the waiter in a restaurant. So good evening, madam and monsieur. I am Monsieur LeBeau (misspelled?). I will be your doctor gastronomic this evening. What brings you to our exclusive five-star French restaurant? Oh, you're hungry? Hmm. Well, let me be the judge of that. When did you last eat? Eight hours ago? You're having rumblings in your stomach, salivation, and an urge to eat food? Hmm. That sounds suggestive, but I think maybe we should run some tests. We would never accept that from a French waiter, bad accent notwithstanding. Chris' mother suggested several times that Chris had asthma. She was told that he can't have asthma under two years of age. Asthma's hard to diagnose. One doctor didn't want to label Chris as having asthma because he didn't want Chris to suffer the insurance consequences. Never asked the mom if she wanted him protected from those consequences. All the mom wanted was an accurate diagnosis. What the solution needs to be is to teach parents the criteria for

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asthma and let them decide whether they have the disease or not. Allow them to do that. The problem is that the doctors, the providers, don't know what the criteria are. They called it bronchiolitis, pneumonia, reactive airway disease. They don't know how to diagnose asthma. The problem is we have a failure at our national organization. The NI's guidelines that define asthma has widespread narrowing of the airways associated with inflammatory cells, et cetera, et cetera. How the hell can I tell if Chris has that or not? I can't look in his lungs. It's not helpful. It's a very academic, abstract diagnosis. What we needed are simple diagnostic criteria to teach the providers so that they can make the diagnosis. And we came up with those criteria. Signs or symptoms of airflow obstruction, variability, recurrence, rule out other diagnoses. Can you show the first slide? And when we implemented these look what happens when providers are given simple criteria to use in order to make the diagnosis of asthma. First slide? It takes a few minutes to get the first slide. What we're going to see is that - this is a group of physicians who took care of patients in a panel of the health plan, and initially in 2002 and January of 2003 about 10% of the patients in their panels had been diagnosed with asthma. After this we provided them with simple criteria and encouraged them to make the diagnosis. The rate of diagnosis went up to 16%. It is a very effective tool. We can diagnose rheumatic fever -- we have criteria for

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that -- but we can't diagnose asthma unless we have criteria.

Madam and Monsieur, I agree, you are hungry. Have you eaten food before? At the diner? A waiter named Joe? Well, I'm sure that was okay, but he's the primary care waiter. I am the specialist gastronomic doctor. Now, here is your selection of foods. You want to see a menu? Make your own selection? I think not. After all, you wouldn't understand it. It is in French. I'll read it to you. Now I think you should start with the escargot. What is escargot? Well, that is unimportant. I'm sure you will like it. Okay, as long as it isn't snails? Allergic to snails? Well, I'll have to make a note of that. Now, for the main course the Salmon Croquet is superb. Oh, wait a minute. The salmon is not covered by your credit card. I'm afraid you can't have the salmon. It's not on the formulary. I'm afraid you're going to have to eat our pasta surpreeze (sic). What's the surpreeze (sic)? Hello? What's the surpreeze (sic)? Well, it's a little bit of everything we served last week. I'm sure you'll like it. Food poisoning? Oh, I think not. Besides it's covered by your credit card so if you get it you'll be okay. Chris got numerous treatments that the mother did not understand. It was in French. She couldn't figure out what he was treated with. Many of the treatments were not effective and Chris' doctor didn't know what the evidence was to help Chris' mom make the decision, like the French waiter who didn't know how to read

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French. It wouldn't make any sense. The doctors have information overload. They don't know what's relevant in the literature, and quite frankly much of the medical literature is quite honestly misleading. Chris' goal, the mom's goal, is just to get treatment that works. Our solution is to try to come up with evidence that actually is effective and what we've done is we have two educators who go out to the private offices of the doctors and spend eight weeks at a time working with them, teaching them the evidence-based practice didactically as well as role modeling and using behavior modification. We show the patient the evidence, let them participate in making the decisions. Like the waiter, if they don't want to make the decision they can be guided. What do you recommend, Waiter? And you can tell them what it is. Now, look what happens when we do this. Can you go to the next slide? That error sign always scares me. It seems like it always happens when you don't want it to. Next slide. What we're going to see is a list of controllers and relievers. Now, with asthma the blue is the relievers and the red is the controllers. With persistent asthma you want to prescribe more controllers. 2000, 2001 very few controllers versus relievers, whereas in 2002, once we've intervened with these doctors, the ratio shifts. When the patients participate in the care and they know what they need to get, they prescribe - these are actually pharmacy pills. The patients actually fill more controllers

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because they understand the need for doing that. That's if the patient's diagnosed, by the way. On the right hand side, if they're not diagnosed they continue to get relievers. Very important for patients to get a diagnosis. Okay, madam, here is your escargot. Oh, that's right. You're allergic to snails. The chef must not have received my note. I'll have to get - take it back and give you something else, though that will take a very long time. You will have to wait. Care coordination is a problem. Information is fragmented. Chris' mother in fact if she wants a copy of her medical records she has to pay for it. If I want a copy for her I don't have to pay for it, but the patient needs to pay for their own records. When their records are available information is poorly organized, inaccurate, illegible, and irrelevant anyway, so it's probably not that helpful. Ideally the mother should be provided with a summary of his medical records including pictures of x-rays and lab results after every encounter. The patient should become the repository for their own medical record. The approach that we've taken in our community is to send copies of the dictation, laboratory, and x-rays to the patients and encourage them to keep their own medical records on themselves and take it with them to the different provider offices. Madam and monsieur, I'm sure you enjoyed the food. Remember if you ever get hungry again you should call right away and I'll give you instructions. Don't eat any of that

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over-the-counter food. You know, the kind you get at the grocery store? Only restaurant prepared food under the supervision of a doctor gastronomic is appropriate for you. Absurd. We would never call the waiter whenever we get hungry again, but Chris' mother was never told what to do if he has another episode. Fifteen emergency room visits, why should we be surprised that he has additional episodes? She was told to call for advice any time he gets sick. The problem that she discovered is that when she did that each provider gave her different advice. And even when they give her advice she didn't have the medicines necessary to do whatever it is that they told her to do. They didn't prepare her in advance. Now health plans do promote action plans. They're in favor of that, but they don't provide education on how to do that. They need to educate the physicians how to use action plans, they need to give them the tools to provide them with, and they need to pay the physicians for the time it takes to write the action plans. Disease specific action plans are universal. They work for diabetes, depression, asthma, the framework for self-monitoring of disease severity, increasing treatment when the patient gets worse, decreasing treatment when the patient gets better. Patients do that anyway. If they do well, that's great. If they do poorly it's called non-compliance because the doctors always want them to take all the medicine all the time. Inappropriate. Patients are much smarter than the

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doctors in terms of that. Now, in Kansas City our tool for action plan is these asthma action cards, and I think the next slide has a larger picture of the cards. I have a number of sets of these if you'd like to look at them and I understand they'll be available up in the front for you to take a look at it. All of our primary care doctors in our program give these action cards to each patient who has asthma. Next slide. And look what happens when you give patients an action plan. This is quality of life. Higher numbers mean better quality of life. Patients are doing better. That is the initial visit the quality of life is 4.6. By visit two, the blue, which is the caregiver quality of life, the mother, her quality of life goes up immediately. The main component of that is reduced anxiety and fear. Once she knows what to do about an episode of asthma, quality of life goes way up. The patient's quality of life eventually goes up, too. It takes a little bit longer. Monsieur and madam, this take-home bag should be eaten as directed. Eat all of the food until it is gone and make an appointment for the next time you get hungry. Okay. Absurd. You wouldn't go to the restaurant every time you need to eat food, but that's what we insist on with healthcare. Chris' mother was told she had to have face-to-face meetings with the doctor whenever she had him taken care of. She could not afford this. Transportation for clinic appointments was a problem. She couldn't take time off from work. And she

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couldn't even afford a clean environment to live in. His house had an unhealthy environment that was triggering Chris' symptoms. And the doctors were complaining, too, because Chris takes a lot of time. His mother calls a lot. Of course she was told to call a lot -- she wasn't given an alternative -- and the doctors only got paid for face-to-face visits. Payment was for what was done and documented, not on how well it was done or whether it needed to be done in the first place. So that's why we have a system that failed Chris. Now the solution that we're working on -- and we haven't been totally successful yet but we're working on video conferencing now -- is e-mail, telephone, web, extended hours, all of those means of communication with the families need to be made available. So we have two options. We can work harder, which is process oriented. We can educate patients, providers, we can grade health plans and use report cards to judge them -- which is somewhat of a punitive approach -- or we can use the second option, which is to create a new system of care, which is goal oriented. Remember it's the patient's goals. And healthcare delivery can be organized, coordinated, and monitored. And the monitoring can be used to improve the outcomes rather than to punish health plans. Now Chris is four years old now and I saw him a few months ago. The mother told me that the family had moved to Section Eight housing. That's more regulated homes so that his environment is cleaner. Chris is now on minimum

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medications. The mother has an action plan. She knows how to follow it. Chris' mother has a complete set of his medical records. She insists on being given that every time she is seen. He's had no emergency room visits in the last year. I was amazed. I asked her, how did you do that? She said, well, it happened like this. A year ago Chris had an asthma attack. We took him to the emergency room, explained to the doctor that he was having an asthma attack. The doctor said no, no, no. I think it's pneumonia. He wanted to get a chest x-ray and give Chris a shot of an antibiotic. At that point she realized that she knew better how to take care of Chris than the doctors did. She left the emergency room, went home, and hasn't been back ever since. She is now empowered. So these five examples is how the patients is a source of control really does unify these themes. The patient as a control really is the unifying factor. I do apologize for the bad French accent. Best I can do. I want to thank you for the opportunity to help us all cross the quality chasm. It's extremely important. It's important for us but even more so it's important for Chris. Thank you very much.

DR. ALLEN DANIELS: Thank you, Jay. A few comments to wrap up this session that I'd like to make. I really appreciate the stories that we heard from each of these individuals and their representative stakeholder group, the communities they represent. Dr. Berwick has very articulately

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described the experience of patients and families as the true north that orients the map for healthcare. Last fall I was at a meeting where a physician told me that he believed actually that the experience of nurses and caregivers was the most important piece of the healthcare equation. And my answer was that the east, west, and south were important directions. We needed to understand where north was to read the map. We've seen today an example as it relates to depression as a beginning point to look at the cross cutting issue of patient-centeredness, evidence-based care, care coordination, patient self-management, and the financial and business case.

Depression and behavioral health is the world that I live in and it's amazing to me the stigma, the problems that occur, and Martha did an exceptional job telling us that story. A similar kind of story in working with a family recently whose daughter was diagnosed with depression. They were very willing for her to have, from their extensive web-based search, Parkinson's or some other neurological disorder, cancer, some kind of endocrine disorder, anything but that dreaded depression. We need to make a better effort to help explain and understand - families and patients understand the disorders and the diseases they struggle with. We need to be able to help those folks to come to terms and build systems that help solve those problems. What we've seen today, really very articulately from three communities, are the stories of how communities can take on

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healthcare, take on the issues of quality, and begin through a process of collaboration, common reporting, common sharing of issue, to begin to establish a set of community priorities and more than that, to take on an action plan. And the part that I would like to underscore here is that action is possible.

Throughout this summit over the next two days, our hope is that you will be able to take these stories, share your stories, learn from each other about the opportunities that exist, and help development the models for quality improvement to help redesign and change healthcare along the lines that are very well articulated in the Crossing the Quality Chasm report.

Again, as we come to conclude this session I'd like to say thank you to Martha and her son for her willingness to share his story, and from the communities to come up here and share with us their experience. So once again, thank you to all of you.

DR. REED TUCKSON: Thank you, Allen, and also again for all of us in the audience, Martha, it takes an awful lot of courage and we really want to thank you. To all of our panelists, you're terrific and thank you very much. We deliberately wanted to start this session, as I mentioned, the subtitle of this conference is A Focus on Communities. And I think Allen is right, that we learned -- and I took a couple pages of notes -- of two things that I think occurred as I summarized my own notes for myself. One is there is a lot

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going on in local communities - that the movement is taking root in communities all across this country. And I think what we heard was some very good and specific examples of where we see successes, but some honest assessments of where communities are struggling against very big challenges. And a lot of those challenges are within the domains of those who have the opportunity for national policy and national healthcare system development and infrastructure advancement. Therefore it is I think very appropriate now to bring our friend, our colleague, Don Berwick forward. Don is a true national treasure. You know him as the CEO for the Institute for Healthcare Improvement in Boston and there is much more about him in your program, but we won't take time on that now other than to introduce Don as a national treasure who will now come forward and give us a sense of then of a challenge really ultimately to all of us as he articulates the gap and lays the issues at the doorstep of leadership. Don, thank you for joining us.

DR. DONALD BERWICK: Thank you so much, Reed, and thank you to that wonderful panel for setting the stage for the work we're going to be doing together over the next two days. I'm very grateful for the opportunity to share thoughts with you about the work that lies ahead, both in this session and more importantly, the time that will follow this session. There's been reference, of course, already to the Chasm report as a framework document for the efforts of the communities that are

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**Crossing the Quality Chasm Summit:
Redesigning Care and Improving Health in Priority Areas
1/06/04**

77

going to be involved in the work that will follow this summit.

Many of you have begun already. In a sense for me to spend the time I have with you reviewing the Chasm report is close to New Castle because so many of you in the room are very familiar with that report and have used it as a framework for your own individual activities. Nonetheless that is what I'm going to do. I'm going to take some time now to walk us through that report, the findings of the committee that issued the report, some of the logic behind the report, and then to help you, if I can, in a translation of the report into the community context that you are now trying to act in. For the majority of you here for whom that is simply a review, I apologize for boring you in advance. You can go get coffee. For those of you, few of you, in the room who need this to bring us up to speed, I think it's probably worth the time. The reason I think it's worth the time is the following. The obstacles to the use of that report as a framework document are very, very high. They will not be easy to remove. Failure is more likely than success without an intense amount of commitment on the part of the people in this room to make that vision a reality. The obstacles -- myths, belief systems, habits -- which lack scientific foundation, which are so deeply embedded in the behaviors and structures of healthcare that one almost sounds ridiculous at the start because there are so many myths being threatened. And the second major obstacle is fragmentation.

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Everything about the way the system's designed, almost everything, mitigates toward separateness, towards individual activity, towards working not as a system at all, and yet the Chasm report is completely a report about working as a system. What can bind us with the structures and support systems and processes and habits and myths of healthcare so fragmenting? The only bond left, the only thing we can rely on is shared vision. There is no other. Without shared vision, without a common sense of what we're going to achieve together, we can't have the clarity and the courage to make the changes that are implied in that report. So building that shared vision is crucial and there is some need for real precision in that vision and that's why I'm going to spend time boring most of you. The Chasm report comes from a history in the Institute of Medicine which has been courageous and effective in its leadership of change. And I think the first piece of shared vision is to understand the Chasm report as a punctuation mark in the trajectory of intellectual development and the foundation for moving ahead to a new system of healthcare goes back decades, probably back to Codman (misspelled?) and Florence Nightingale, historically. But there is in the Institute of Medicine context and a national leadership a story which begins in the mid 1990s with the assembly here in the Institute of Medicine of a roundtable, a format for conversation and declaration by the Institute short of a full

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report. The Institute of Medicine roundtable was a fundamental turning point I believe in the country's understanding of the quality issues that we're tackling now. That roundtable was followed by an advisory commission that President Clinton set up and that Janet Corrigan was the executive director of under Donna Shalala and the Secretary of Labor, Alexis Herman. I want to pause for a moment and say something that needs to be said in the context of this. There is no leader in American medicine that's been more central to the formulation of the agenda that you are about to pursue than Janet Corrigan. Her presence throughout the entire history of the development of this is an active personal, dignified, and I must say quiet leadership that everyone in this room needs to understand. The President's Advisory Commission was simultaneous with another finding of the National Academy of Sciences by the National Cancer Policy Board, which is a joint function of the NAS and the IOM, which made essentially statements on the state of quality of American healthcare with respect to cancer care that I think is fundamentally a chartering document as the roundtable report itself. And all of that culminated in the program that Janet leads here, the Institute of Medicine Program of Quality of Healthcare in America, which is the launch pad for the vision for change in American healthcare. The roundtable remains fundamental and what the roundtable did was convert public understanding - not scientific

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understanding. We already had that. But public understanding of the nature of the challenge we're tackling from a belief that the problem of care that Mrs. White-Cotton described is an isolated, stochastic, event in the corners of care. That there are bad doctors or bad hospitals or bad events, which do not characterize the care system as a whole, which we need to get out of the system, which is the conventional belief. The IOM roundtable rejected that belief. With enormous amount of energy in review of scientific data it concluded that the problem of quality of care, the experience of the patient in American healthcare, is not a problem in the corners. It's a problem in the center. One of the key sentences -- in fact I would declare this to be the turning point sentence in the history of this analysis -- appeared in the neat article in the Journal of American Medical Association in 1998, that the roundtable reported out, and this is a phrase from that article. Serious and widespread quality problems exist throughout American medicine. These problems occur in small and large communities alike, in all parts of the country, with equal frequency no matter what the care system, and very large numbers of Americans are harmed as a result. Ms. White-Cotton, with enormous generosity, characterized her experience in depression as perhaps somewhat unique to the experience of patients with depression. I must tell you it is not. She is describing the central experience of the American patient with

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chronic illness, or facing the end of life. Patients whose needs compound the fragmentation of the healthcare system. Depression is not a different problem, it is an iconic problem and the Institute of Medicine declared that in 1998. The evidence-base for this is extraordinarily big and it would take all of the two days to even begin to fill a fraction of the evidence, on the basis of which that roundtable issued its results. This is a fragment. It comes from the work of probably the most significant health services researcher of our time, Professor Jack Weinberg at Dartmouth. But for condition after condition he's done the same studies. This is a study of congestive heart failure hospitalization experience for Medicare enrollees in the mid 1990s. It's the same data now that I - you wouldn't notice any difference if I showed you experience in 2003. The blue dots each represent a hospital service area. One of these is going to be a hospital in Flint, Michigan. Another of these is going to be a hospital in Kansas City, a hospital service area. Trust me, statistically defined in a meaningful way. Each blue dot is a hospital service area. The vertical axis is a measure of the likelihood that a Medicare beneficiary will be hospitalized with congestive heart failure in that hospital service area. And look at the variation from the bottom to the top. We're seeing areas with hospitalization rates below 10 per 1,000 beneficiaries, up to areas with 40 per 1,000 beneficiaries. That's a 400% variation

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in the likelihood that a person with congestive heart failure will be admitted to a hospital. Now there are lots of possible explanations for this and you can believe that the army of health service research in America has been trying for decades to understand the sources of variation of this hospitalization rate. And so we've acquired the capacity to adjust to these rates for enormous numbers of potentially confounding, misleading variables that have nothing to do with the care received. We're looking here primarily at residual variation, variation that no rational person in my opinion can any longer attribute anything else than the quality of care being received by the patients in these communities. Some communities are capable of keeping patients out of the hospitals, others are not. So this variation in care begins to be an indicator to the IOM committees that have looked at this that we have high variability in the likelihood that patients around this country will receive proper care. Here's some data that the IOM did not have at its disposal. It was produced by Professor Brian Jarman (misspelled?), who is currently the President of the British Medical Association, but is a leading British epidemiologist and just spent a year at my institute as a fellow, and we handed him the Medicare database, the Medcard (misspelled?) database for five years, as well as other databases. In this case one from AHRQ, the (unintelligible) database. And Brian has been studying a different probability.

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Not the probability that patients get admitted to hospitals. In this case the probability that a patient who's admitted to hospital will die. And once again Brian is a world-class epidemiologist and you will now, as you look at these data, begin to have a bunch of explanations in your mind. Did the pattern of ages of admission to hospitals differ here? Are these patients at different risk at the initiation of their care? Every dot's a hospital - an American hospital. Two hundred and fifty randomly selected here. The vertical axis is a measure of the probability of deaths standardized to America - to an American average of 100. A hundred is not ideal but it's the average. So 100 on the vertical axis means the average probability that an American admitted to hospital will die during that hospitalization. Every dot's a hospital and the vertical axis varies from about .4 to 1.6. That is a 400% variation in the probability that a patient admitted to an American hospital will die during that admission, adjusted in this case for approximately 110 variables. The only residual explanation for this wide scale variation that I think a responsible health service researcher can assume is that at least some substantial degree of that 400% variation is variation in the quality of care that these patients receive. We have researchers in this room that have contributed substantially to the literature on variations just like this. Steve Jenks, sitting there, working with a CMS database

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publishing landmark articles in the Journal of American Medical Association and elsewhere. Study after study, researcher after researcher, with almost no exception at all have been able to document extraordinary variation in the state of patients admitted to American hospitals in the mainstream, not in the corners. Efficiency and cost are qualities of the care system also. And every bit of discussion we can have about the variability of the outcomes of patients can be applied to the way the system uses resources as well. And that's what the horizontal scale on this diagram shows. It's the amount hospitals get paid for the care of patients. And as we saw 400% variation in death, we see a 500% variation in the payments these hospitals receive, adjusted for 110 variables including market area labor cost. And there is no regression coefficient at all. It's zero. No relationship whatsoever between the amount the organizations get paid and the probability of the patients admitted to those hospitals will die. This is a taste of the kind of information that the Institute of Medicine roundtable and its successor and probably committees - the President's Commission, the National Cancer Policy Board, and now the Institute of Medicine Program of Quality of Care in America are dealing with. You're dealing with a problem documented in science better than almost any health services research problem I know of. Problems in the quality of care. Its effects on cost are substantial and we

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see here the continually rising cost of American healthcare during a period in which there is little or no documentation except for a few isolated diseases of improvements of outcome of care whatsoever. The United States is distinctive in its wastefulness as it achieves quality of this low quality - or quality of these low levels. The United States currently spends more -- 40% more -- than any other western democracy on healthcare per capita, despite the fact that it has a somewhat younger population than many of those democracies that spend far less per capita. And in which our outcomes of care are in general no better than, and in many, many well-documented cases, worse than care in these other countries. We spend more and we get less. The Institute of Medicine roundtable began to give us this shared vision in the form of a shared vocabulary. We have a language now supplied to us by the Institute of Medicine, which should become the conventional language for our conversation of what we now intend to achieve. The original language, the source language in 1998 for the roundtable were three words that began to give us a stratified view, a parsed view of the nature of the problems I've just given you a hint of. They use the language overuse, under-use, and misuse. You've heard Allen and Jay and other people on the panel use those terms. Overuse was the Institute of Medicine's roundtable's term for doing things to people that cannot help them -- visits, operations, tests -- applying resources that

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have no chance of helping the patient, or such a minimal chance that the use of resources is very unwise. We have many, many documented cases in the health services research literature of overuse of care. No matter which of the 15 communities you are in they abound. They abound in your community. Things are being done to patients in communities that cannot help them. Thirty percent of the children in the state of Colorado in an important Medicaid study a number of years ago were found to be receiving excessive unnecessary antibiotics for their ear infections. We have from the Rand Medical Outcomes study and the Health Insurance Experiment and successor studies evidence that as many as 20 to 50% of surgical procedures, when studied with respect to the needs of that patient's versus an evidence-base, should not have been done. They were unnecessary and scientifically unjustified. At least half of the images we do with the patients with back pain and other conditions are unjustified based on scientific ground. We overuse intensive care and invasive care at the end of life. Joanne Lynne (misspelled?) is in this audience. You're my heroes. Joanne is one the great leaders in our country in terms of her knowledge and understanding of care at the end of life and for patients with diseases that are not going to go away. Many, many patients who die, die in intensive care units, and there's variability here as well. We know from the support study sponsored by the Robert Wood Johnson Foundation and from our

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hearts that a patient who is now in the last stages of their illness rarely, infrequently wants to die in an intensive care unit, intubated, isolated from their loved ones, invasive, expensive, and (unintelligible) procedures. And yet hospital service area - at a hospital area the probability that a patient at the end of their life will die in the Medicare system ranges from about 6% in the communities with the best support, hospice care, outpatient alternatives, to dignified - to as high as 30 or even 40% in some other communities which have no alternatives, no other place for patients at the last stage of their lives to die with dignity in the presence of their loved ones. The consequences in the United States in cost are extraordinary. We spend about \$5,000 per person per year in this country now to provide healthcare. There is variation in that as well within our nation itself adjusted for important variables about the demography. We now know that there are communities and areas in our country which are able to deliver care at substantially lower investments with documented outcomes as good as other areas. Appleton, Wisconsin, is at \$3,400 per person per year, whereas the other states average 5,000. Miami, Florida is up close to \$8,000 per person. You might expect that these variations in investment would be associated with variations in outcome - more money spent, better outcomes. No such luck. There is no evidence that the highest expenditure regions of this country are the

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ones that are achieving the better outcomes. In fact there is evidence to the contrary. A landmark study in the American Journal of Medicine just three months ago, Elliott Fisher, protégé and now colleague of Jack Weinberg published a study that should be mandatory study for everybody in this room, which has divided American healthcare expenditures region by region into quintiles. That is the lowest fifth, next fifth, up to the highest fifth, and regressed and analyzed outcomes of care, quality measures in those communities, against the quintile of membership and there is a relationship between quintile and quality and it is negative. The higher expenditure, the lower the quality of care in process terms, not just outcome terms. In fact the highest quintile is by far the lowest quality area in America. American healthcare in other words could shift, if it could figure out how to do so, to the lowest quintile of care in our nation and achieve quality higher than we are now achieving at the median, let alone the highest quintile. It gets worse when you look international. Our country spends, as I say, about 4,000 - \$4,800 or \$4,600 per person per year. These are \$2,000 as supplied to me by Uwe Reinhart. He didn't give me the dollars, he gave me the slide. The OECD median in Western Europe is \$2,000 and I can vouch from my many trips to European countries that the quality of care achievable now in many western democracies, including those well below the \$1,900 figure

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vastly exceeds the American level of quality of care at less than half the cost. We need to develop, in my opinion, extraordinary new levels of international curiosity about how those systems achieve what they do. The Swedish system does not operate at 40% of our costs with better outcomes than the American healthcare system because they're blonde. It's because they built a system smarter than ours. Under-use exists as well. We heard that from Mrs. White-Cotton. Lots of people who could benefit from things don't get those things. And we have good documentation of those failures. They're in the Chasm report and they're in the many, many background documents to that Chasm report. And we have a problem which I will call the problem of reliability of delivery as well as overuse of delivery. We cannot seem to be able to promise to people things that will help them with reliability to expect from our automobiles, our toasters, and our grocery stores. Ms. White-Cotton gave us an extraordinary compelling image of what under-use feels like when it reaches the patient and loved ones. The third basic category of problem that the roundtable flagged for us was they called misuse. Misuse means screwing up when we try to do something, whether it's overuse, under-use, or right use. It's doing it wrong in such a way that the person gets hurt. And here we have compelling, difficult, shocking evidence that seven out of 100 Americans in hospitals still suffer from the ill effects of a medication error or

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could from a serious medication error. And as you know from the report that preceded the Chasm report, the report called To Err is Human, we in the IOM believe that somewhere between 40,000 and 100,000 Americans probably die each year in hospitals from their care. They're killed by their care. They're not killed by their disease, they're killed by their care. In its initial summary of its review of the safety issue, To Err is Human, the IOM took a fundamental step forward beyond documentation of the issues, which the roundtable had done, began to explore the system implications. And the three fundamental findings first in first report of the IOM committee, To Err is Human, I think there were three basic assertions. There is a problem, Houston. We really are killing people in healthcare and it really is risky to get admitted to an American hospital where it would be absolutely unacceptable in any other industry. If known should be a source of outrage. In fact in some sense if you're not angry at the situation, you're not part of the movement because the situation is bad and that's what the report said. But it said the anger ought not to be directed at the healthcare workforce. It is not the doctors, it is not the nurses, it's not managers, it's not the individuals. The finding in that report is a scientifically grounded conclusion that to blame the individuals who work in healthcare for the defects of healthcare is not - it's not just unkind, it's scientifically

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inaccurate. It's a misunderstanding of how bad things get into complex systems. Most patient injuries, said that report, *To Err is Human*, are due to failures in the way we built the system. The plane crashes because of the way we built the aviation system, not because that pilot is at fault. More often than not 1%, 2% of those failures, yes. It's due to a miscreant - alcoholic clinician, a person who no longer cares for some reason. Someone depressed, someone who is incompetent, someone whose Alzheimer's not yet diagnosed. Yes, individuals can cause harm. But 98 out of a 100 of those harms are attributable back to the way we built the envelope in which that individual good-hearted doctor, nurse, clinician, pharmacist, respiratory therapist is trying to work. That is upstream against the American belief system. I said we have myths in our way. The myth of individual miscreants as the source of defect is very, very durable. And an important step to take these two days is to throw that myth overboard and get started on a scientifically correct view. The unscientific view is that this is something about individual - and as a USA Today article said last year or so -- I clipped this out -- *Is Your Doctor Bad? You May Never Know*. If something goes wrong it must be a bad doctor. No. The scientifically correct statement is if something goes wrong it probably isn't a bad doctor. It's probably a good doctor trapped in a system that any other good doctor would get trapped in at about the same

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frequency. This myth of blame produces a predictable response when Jack Weinberg publishes his data or Elliott Fisher publishes his data or Steve Jenks publishes his data. When you begin to look at defects from the viewpoint of the myth of individual responsibility, you go through what I would call the Kugerah (misspelled?) stages of dealing with the reality of defect. The first is to say it's not a problem. The data are wrong. There's a flaw in the data. Somebody didn't adjust. I can think of a variable smarter than you. And you cannot. I will tell you you cannot. At this point the health service research community has gotten smarter than you at adjusting the data for the things that you worry about. More or less, by and large, enough - plenty enough for you to know that when I show you that scatter plot you're looking at variation and something you should care about. If we overcome the data are wrong dilemma, the next Kugerah (misspelled?) stage is to argue that, okay, the data are right but that's not really a problem. I can't quote the bumper sticker because it's obscene, but it's, you know, stuff happens. It's the idea that the defects are somehow inevitable in life. People die, drugs get screwed up, the phone doesn't get answered. It's the way life is. Suck it up, patient. We can't do it right. That's what life is like. And then we begin to blame the patient for telling us there's a defect there because what we're really saying is the patient doesn't have the maturity to

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understand that stuff happens. Stage three of Kugerah (misspelled?) is the data are right. Okay, it is a problem, shouldn't be there, but it ain't my problem. That's Medicare's problem. That is the trial lawyers forcing me to do this bad thing. That's the fact that the phone company doesn't make good phones. Anybody but me is responsible for the defect and so I, we, can't take responsibility for a defect we don't cause. Stage four is where you need to be or get if you're not there yet. It's beyond the sense of guilt, beyond the blaming someone else, beyond the denial into a stage which I think is accepting responsibility. The Japanese term is jaseki (misspelled?), I got it. My problem. And that's where this summit needs to be. That's where you all need to start. It is a problem. American healthcare is poor, not good. It is poor, not good. American healthcare is too expensive, not underfunded. American healthcare is wasteful, not squeezed. American healthcare has abundance, not scarcity. We need to change the way we think and own the problem of making the changes the Chasm report knows. And nobody in this room, no community, will move forward into the Chasm report until it's progressed to stage four. If you're not in stage four you're not in the program. Now, you don't have to work from a sense of helplessness. If you want to own the problem and don't want to feel depressed, move to optimism. And the optimism we have is science. It's the scientific understanding of what makes

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quality happen in the first place. And this is the scientific understanding. The qualities we care about -- safety, effectiveness, patient-centeredness, timeliness, efficiency, equity -- those are qualities of design. The speed of my car is a quality of the car. When I owned a Ford Windstar van it's maximum speed was 90. That's it. Couldn't get it higher on the Bonneville Salt Flats with high-test gasoline. Ninety is it. If I want 140 I could yell at my car, I could sue it, I could blame it, I could put an incident report in its file, the car will not go faster. It cannot. Ninety's the top speed of a 1993 Ford Windstar. I guarantee it. If I want to go faster what do I need? I need a new car. I need a different car. Now, with cars I have to pay more. The secret in healthcare is I don't need to pay more to get healthcare at 140 and that is what the Chasm report is beginning to offer us the opportunity to do. Top speed's a quality of cars. Safety's a property of the way you have your current system built. Delays, waits, the defects Aaron experienced. The qualities are built into the system the way it was designed. If we want new system we need new designs. In the IHI, my organization, I think we should have on our letterhead this first law of improvement I call it. Every system is perfectly designed to achieve the results it gets. When Kansas City, Memphis, if you don't like your results, change your system. There is no other option. The Chasm report is the design of a Jaguar. It offers you a

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blueprint for a car that can go 140. A system the doesn't have to exceed to the conditions of performance that the Institute of Medicine roundtable and the President Advisory Commission its successor work in the IOM document (unintelligible). Chasm report is an architecture. It reaches the same conclusion as the Errors report. The problems are very serious - very, very serious. H4 is required. We look at them and say we have them in Flint, in Kansas City, in Memphis and every community in this area, and every organization in this room. The problems do not come from the people. They're coming from the designs of the care and I think a key sentence in this report reads, in its current form, habits, and environment American healthcare is incapable of providing the public with a quality healthcare (unintelligible). It is incapable of treating Aaron White-Cotton. Incapable. It cannot do it. It must change to be able to meet Aaron White-Cotton's needs. But it can change. There are designs. We can fix it. Science provides us with some answers. There's science we already have that provides us with answers we can implement. There's science we badly need but can invest in and get answers just like we can get answers to membrane transport problems or the problems of bronchospasm in asthma. The key is change. The Chasm report is a call for change. The intellectual architecture of the Chasm report is (break in audio). All will be necessary. This is a system of changes in which change at any one level alone will be

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completely insufficient to treat Aaron White-Cotton. The reason why this project is so exciting to me is because in your - in the room from each community you can or could - you do have or could have agents of change who, given shared vision and intense commitment and stage four in front of your reality, are capable of organizing a system of changes instead of hoping for some magic bullet somewhere on this diagram that it'll - that alone can change care, even though it can't. The four levels of change are as follows. The first is change in purpose. It's sort of weird to see change in purpose up here as a system idea, but it is a fundamental idea. There is no system without a name. There is no system. The clarification of purpose is a precondition -- precondition -- for the rest of the changes needed. Now, I believe, as Allen generously quoted, that the compass is the patient. True north lies in the experience of the people we serve. We exist for no other reason than to relieve suffering. There is no other reason to spend this money. No other reason to be in this room. Any other reason is to be subordinated to the relief of suffering. And suffering lies in the experience of the people we help and therefore their experience tells us what to do. There is no other answer. We must know it, measure it, respect it, honor it, and treat it not as a hassle or as a problem or as an unrealistic expectation, but as the purpose of being. The purpose of your organizations is not to survive. The purpose

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of your organizations is to help Aaron White-Cotton survive and no other reason. And so studying and clarifying the experiences you wish to produce is the chartering idea behind the rest of the system aims we're going to after. But it is change. It's a change to adopt what the President's Advisory Commission said, that the overarching purpose of the healthcare system, and ratified in the Chasm report, is to continually reduce the burden of illness, injury, and disability, and to improve the health status and function of the people in the United States. The Chasm report offers you a dimensional view of those aims. It - one step further. It said, well, what we really mean is six things. Six things you need to achieve - six gaps to close, six dots to move, six system level results to work on. Please, make people safe in our hands. As safe in our hands I would say as they are in their own homes. Let's not kill people in healthcare. Let's avoid that systematically. Let's make that number -- 44,000 deaths a year -- fall steadily in America step-by-step, community by community, hospital by hospital, measurably fall to zero. Let's aim for zero. Safe in our hands. Effective care. That's overuse and under-use combined in a single word. What the Chasm committee did is take the roundtable words, overuse and under-use, and bond them into a single term, effectiveness, meaning do what helps and don't do what doesn't help. That's equivalent almost to matching care to science given patient

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preferences. You have to factor patient preferences in order to be effective. The Chasm group went beyond the roundtable. I'm very proud that it did that. It built on the roundtable's work but it said, you know, quality is not overuse, under-use, and misuse. It's not just safety and effectiveness. There are other dimensions and we're going to put those right on the screen as well. We're big enough and mature enough to do it. And so the third dimension is patient-centeredness. The ultimate judge of the quality of our work is the patient, end of story. And therefore we must learn to honor the individual choices, respecting the variability in preferences, the variability in need, the variability in ethnicity and diversity, and the need structures and habits and spirits of the people we serve. Honoring the patient, patient-centeredness, the patient as a source of control was put on the screen by that committee. The fourth is timeliness, which Ms. White-Cotton spoke to very eloquently. Timeliness is an extremely valuable property of the system, not mentioned in the roundtable report but centered in the screen of effectiveness for American healthcare from the Chasm report. Efficiency - waste is un-quality. You give a drug that can't help you're not only ineffective, you're throwing away money. When you order two tests instead of one you're not just being ineffective, you're throwing away money. When you duplicate efforts, when you forget it and ask the patient to do it again,

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when you require two visits instead of one, every time you put in a resource that doesn't help you're wasting money and waste is un-quality. And then equity - I agree with the comment that it might be job one. That the best test we can do on an American today, the test that will predict the outcome of their lives, that will tell you how long they will live, how much asthma they will have, what their health status will be, the best test is very, very inexpensive. Just look at the color of their skin. Knowing someone's race in America tells you more than anything you can know about their blood on a randomly selected American about their future. And a Black male born in Baltimore next year will have a life expectancy eight years shorter than a White male. And so this gap in racial and ethnic quality is labeled by the Chasm framework as a quality problem. And so this is the charter. Safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity. And the Institute of Medicine - Institute for Healthcare, my organization, we're fiddling with terms for the public. No needless death. No needless pain and suffering. No unwanted waiting. No helplessness. You will be in control. No waste. Clarifying aims for improvement is the first major change contemplated by the Chasm report. Every community in this room will have to do so at a quantitative level, and I think will have to ask itself how it will know. You'll find these in the recommendations in Chasm report. This was a report

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**Crossing the Quality Chasm Summit:
Redesigning Care and Improving Health in Priority Areas
1/06/04**

100

recommending basically to the Congress and the President so you have to translate into community terms, but we said please endorse the statement of purpose, understand you exist not so your institutions exist. Institutional survival is not an aim in American healthcare. Patient well-being is the aim of American healthcare. Own that as a community. Endorse the aims for improvement in measurable terms, and link it to measurement. If you don't know how you're doing you can't get better. If you don't know where the golf ball went you can't get better at golf. If you don't know your level of effectiveness, if you don't have data like we saw from Kansas City, you can't make progress against the enemies of disease. How? What's the Jaguar? What's better than a Ford Windstar? Chasm report describes the care system. Evidence-based, describes the care system, which that committee, we, have enormous confidence would result in a top speed far higher than the current top speed. Do we know that for a community? Sort of yes and sort of no because everyone on that committee, and you most of all know that the design of the car has to be adapted to the local climate. And so the Chasm report is not a detailed blueprint. It's a high-level blueprint. The details lie in your hands to figure out how to make this attribute a property in an area which has a southern accent or high mountains or high temperatures. You have to adapt the Chasm vision to your community, which is a hard piece of work. But

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the framework is there described as Microsystems capable of delivering the care that Aaron White-Cotton needs. I think behind the Chasm report framework are three fundamental design rules, which would be the touchstones for everyone in your community - knowledge-based, patient-centered, system-minded. There's a tough edge to this one. If we're going to be knowledge-based and there is someone in your community who says no, no, no, medicines and art, I don't care to use the knowledge. If we're going to be patient-centered and there's someone in the community that says no, no, I don't want to do that. I'm much smarter than the patient. Or system-minded and somebody in the community says no, no, I do my work best, leave it to everybody else to do their work best. I'm not going to cooperate. We must have the courage in our communities to tell those physicians or nurses or managers or boards of trustee members, you are in the wrong community. There may be some place that will want some of what you bring, but if you can't bring enough to us to be helpful. Knowledge-based, patient-centered, system-minded is the science-based architecture of the future care system contemplated in the Chasm report. That was translated into ten simple rules for design. These are draft quality. They're not simple and they're not even rules, as Bob Waller from Mayo Clinic says. But they are hints. They're ideas about the design principles against which to model care. Care must be continuous to a relationship. Care

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is not visits. We have not succeeded by having a good visit or a good hospital admission or a good phone call. We have succeeded by establishing a good, continuing relationship with Aaron White-Cotton so that he will not be forgotten. That his care is described as a journey, by him and by us, instead of as an event. Care has to be customized based on the patient's individual's values and needs. What do they need want accomplish? Success is only accomplishing what they want to accomplish, not what we want to accomplish. And so variation must enter the system at the patient level based on patient preferences. The third design rule is the patient is the boss. The patient is the boss. The patient has the information, has the ultimate right of decision, has the right to tell us what values to implement in care, has the right to tell us what risks should be taken, what risks not to be taken. Sharing of information and the free-flow of knowledge, including patient carried medical records is an essential pre-condition to patient control. Chasm report says patient should have unfettered access to their medical records. Unfettered access means unfettered access. No cost, no barrier, no limitation. My own prescription is to give every patient their medical records in Flint, Michigan, end of story, tomorrow. The fifth element of design is to use evidence. That is base advice to patients, the general guidelines for care, on the best science we have. It's a forte in American medicine that we have

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scientific reservoirs for such guidance. In this room is Gordon Mosser from the Institute for Clinical Systems Integration in Minneapolis. He's developed hundreds of guidelines - evidence-based, carefully researched, well updated, put in convenient forms. This country could make a great leap forward. Every community in this room could make a leap forward to be evidence-based by saying starting tomorrow we use the ICSI guideline until we improve it, and we will have leapt into evidence-based care based on evidence-based guidelines of the best possible quality. Safety's a system property. Let's stop killing people but not by asking pilots not to crash, or doctors not to kill people. They didn't come to work to kill people. People get killed in American healthcare due to system flaws. We need to stop it. Or the workforce as well. Need for transparency - there is no improvement in darkness, only daylight. And so the American habit of secrecy, hospitals that won't talk about their outcomes, that won't share reports, the insurers that won't share data because it's, on selfish grounds, important for them to hold data tight, to end that behavior. American healthcare needs to be openly transparent so we can learn from each other. Which of those communities has the lowest congestive heart failure admission rates and how do they do that? It's a question in daylight, not darkness. Chasm report asks for anticipation of needs, which is an engineering idea. We need

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to understand flow, continuous flow, and apply it to our system so we're not being surprised when patients show up. Chasm report calls for a continuous decrease in waste and above all for high levels of cooperation. I once visited a village in Alaska and asked the native council what they were trying to achieve, and they gave me a list of ten healthcare goals. And the first one was beat alcoholism. And then they said, no, no, it's really two lists and they handed me another list that had alcoholism written ten times, the other nine goals on a different piece of paper. Cooperation needs to be written ten times here. It is the fundamental redesign idea. In fact, as Jay said, if we get patient control right we'll be on the right track. If we get cooperation right we'll have the right designs. It works. David Stevens (misspelled?) is in the room I think, or certainly - are you here, David? Oh, stand up, David. This is an American drill. David has been the leader at the Health Resources Service Administration. He's now at HRQ, but David is the person who caused change in the American healthcare community health center system. In hundreds of community health centers in this country we are now seeing dramatic improvements in the care of diabetes, congestive heart failure, depression, the same hit list -- asthma -- that you have here. They have had successes. They did it based on science. Scientific design. Evidence-based medicine doesn't just mean using the right drugs. It means evidence-based

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design of care. Designing care systems that lie in evidence. We have for chronic disease care for every one of the list of conditions you're working on, the work is done. It was done by Ed Wagner and his colleagues at the MacColl Institute. I think Brian Austin's in the room from MacColl. They're assets to this project. This design, a chronic care model for what care should look like at the community level, every institution owning its share of this, funders funding this, measurements committed to it produces better results. We know it from the implementation of that model under David Steven's leadership at HRSA. We know that they have been able to drive hemoglobin A1C levels down in the poorest care settings in America by over one milligram percent - by 1% -- one absolute percent -- which if you follow the UK PBS model would result in about an 18 to 20% reduction in all caused mortality and cardiac endpoints for the 35 - now 60,000 patients in registries in the HRSA database. It can be done using evidence-based models. The Veteran Administration has been a leader in the safety arena and in the reliability arena. This was a report in JAMA showing - comparing teaching hospitals to non-teaching hospitals and their reliability of use of proper medications for heart attack victims. The blue bars are teaching hospitals. The red bars are non-teaching hospitals. And the paper reports that the teaching hospitals are better than non-teaching hospitals. Yes, indeed they are. Teaching hospitals have a success rate,

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for example, in beta blockade use of 49%, a defect rate of only 51% compared to American non-teaching hospitals with a defect rate of 65%. But go to the Veteran's Administration your defect rate is zero, at least in the Mid-Atlantic area and the Ohio Valley. Their Veteran's Integrated Service Network 15 is now virtually wiped out - unreliability in the use of beta blockades. Could be done through system design. The Chasm report says, okay, get through redesign communities. It will be hard. Anger will rise. There will be people who will tell you they won't play and then you must tell them then they cannot play. Adopt the new rules for care, modify them for terms appropriate to your own setting. To start somewhere, how about the priority conditions? The Chasm report said 15, the IOM upped it to 20. You've got to set a close eye. Here, five? Anywhere is better than nowhere, and you've got five important conditions to work on in your communities. Get to work, apply the new rules for care there, and invest in the innovation we need. We called for national innovation. The Congress and the President have not responded to this. We have not had a public policy commitment to innovation error. We will work very hard to get that, but innovate locally and learn from each other. The micro-system work occurs in an organizational context and the redesign of organizations is the third tier of change - the third part of the integrated network of change called for in that report. Organizational changes

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are asked. They are needed. They're called crosscutting issues in this conference. They include redesign of the search systems for finding out who does it better, redesign information technology, redesign of our concept of the workforce, the way they're supported, the way they're trained, the way they interact with each other. Redesign of the measurement systems so we know where the golf ball went. Those all lie at the doorstep of the organizations - the payers as well as the deliverers of care who need to commit fundamental changes in care processes, information systems, HR, teamwork, any of the cross-cutting issues we'll be discussing in the next days relate to organizational - and the fourth level's the environment. There are toxicities in the environment which prevent priority of aim. They prevent micro-system redesign and coordination of care. They prevent the ten simple rules. They prevent organizations from investing in what they need to support and it would be great if we could get some reform at that level. The exciting thing about community level work is we get a shot at the environment. You have a chance to actually raise issues which normally can't be raised because there aren't enough payers in the room. There are payment issues in terms of conceiving about - of the nature of care itself. I was shocked to hear that story about the dishonesty, I guess - unwitting dishonesty between what is perceived to be a benefit and payment for depression care when the actual

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behaviors are not payable. Time to engineer that out of the system. Is care is continuous healing relationship then you need to pay for continuous healing relationship. If we have aims and want results we should pay for the results, not for other things. And so the alignment of the payment system is a tremendous opportunity. We need some experiments on that. No one really knows how to do it. There are new workforce designs that are needed and we probably ought to get to work harder on (unintelligible) reform. I must editorially -- this is not in the Chasm report -- I am impatient with blaming the environment. I do believe that it is possible -- harder, but possible -- for the other three levels to take important, urgently needed, and successful action that the environment does not change. At any rate life is too short to say I can't change because someone else won't let me. And so the core conclusions of the Chasm report stand. There are problems. It's not that people stopped that myth, the design, and there are designs that would help. Now let's take it one more step at the community level for a couple minutes. What would it mean at the community level to deal with level one, aims? It would mean the community. Whatever that can possibly mean to adopt the aims (unintelligible) would tell me how safe, effective, patient-centered, timely, efficient, and equitable when it will be. Unless you're willing to put a stake in the ground as you would with literacy or air quality or the

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achievements of your community economically, you need to think that way about healthcare. Un-quality is pollution and we wouldn't breathe air with particulate levels above some level. Don't get healthcare with safety levels below some level. Don't buy ineffective care. Don't buy unsafe care. Don't buy care that isn't patient-centered. We need to put a stake in the ground at where we're going to bring our community. No one's done that. Not the President, not Congress, no one's done that. We do not have leadership at the national level for the declaration of how good we will get. You can do it. You have to do it because no one else will. And then develop a community-wide measurement system that will let you know how you do. If you can't commit as a community studying the effectiveness of your progress, it will be extremely hard to know which changes helped and which didn't. And so there's an intimate relationship between declaring an aim and deciding to see if you get there. It's not for judgment. It shouldn't even be for reward or punishment in my opinion. It's just to know how we're doing, because we're going to make changes and only some will be helpful. We need to know which ones are. And review the progress. Not annually was what the President should do. Your community needs to review progress frequently - monthly, weekly, I don't know. At some frequent level so you can track at the pace you want to make things better for the people you serve. Now you have to change the micro-systems.

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What if your community can say in our community, if you move to our town, your care honors the ten simple rules? We promise it. In fact we made it very uncomfortable. If doctors or nurses or hospital administrators or board members don't adopt those rules as what they think the care should be, they often leave town because they don't like it here. And frankly we're happy to see some other community get them. Because the people that work here honor those rules. That's the vision of the care we're going to build in our city. Payers know it, organizations know it, the micro-systems know it, we promise it to the patients. The new care would look like this. There would be enormous amounts of non-visit care in your community. E-mail care, phone care, group visits, Internet access. You would widen the bandwidth of opportunity for patients and families to interact with the system. In standardized care in science you'd be very smart to see Gordon Mosser after my speech, get the ICSI guidelines and implement them. End of story. You can save yourself years. Just decide that we are an ICSI community. In our community we use those guidelines because we don't (unintelligible). Put patients in charge. Implement shared decision-making. Find the mechanisms that allow Aaron White-Cotton to say what Aaron White-Cotton's care really should be. Ask him. Find the mechanisms through which the risky decisions are made together with the patient. Free-flow of knowledge. Put your care on the web. Figure out a way

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to make the care systems public. Tell the patients what you're going to do for them and ask them to tell you if you did it. And give every patient their medical records. Every patient their medical records. I think that will be a fundamental step forward if we can shift and do that. I know all the opposition. I know all the concerns. Do it as a community. Be the first community in America. If you live in this town you own your medical records. They belong to you. Carry it with you. Use registries. Community wide registries will crack the nut. We will know how we're doing. Every asthma patient's in an asthma registry if they're willing to be. Every congestive heart failure patient's in a congestive heart failure registry. And it doesn't matter where in your town they go, with their permission, (unintelligible) HIPAA, with their permission we know about them and we can promise them that we won't forget. Aaron's care got screwed up because we have amnesia. We are brain dead. There's no memory of Aaron from one place to another. Let's end the story with registries. Reduce waste in all its forms. Do a test for another nickel. Don't ask for another nickel. There is plenty of money in your community (unintelligible) needs. I know it. Elliott Fisher knows it. Jack Weinberg knows it. It's time to end the myth that we don't have enough money in our healthcare. We have 40% too much. And put cooperation for the main value for working in your community. If you can't cooperate you

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can't be here, would be the ultimate (unintelligible). The organizations need to support it. They need to change. I think the fundamental change is the hardest, it's impossible, it's fact, it's utopian. Organizations need to somehow in healthcare give up the notion that their own survival is the reason they're around. Their survival needs to be put at stake under the service of the patient. If the organization needs to end, move, change, be a different thing, it's got to be an option. If your board of trustees doesn't believe it you probably shouldn't be in the project. How the organization can help is with help with that information problem. Build healthcare infrastructures starting with the disease you've chosen for the entire community. Adopt uniform electronic medical record for your community. Let's end that. Let's make healthcare as modernized in record keeping as pizza joints are, okay? Put the patient's record on the computer. Find a simple electronic record and make it the community record. It's the Memphis record. It'll be the Kansas City record and standardized at least for the community as we cannot for this country. Use community-wide registries that will have to be institutionally supported. Individual physicians will not be able to do that. You'll have to train people on this. The ten simple rules are not simple and it's going to take a long time to have community level source building so people understand the basis of action that makes it acceptable to work in this

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community. Effectively, maybe not economically, but effectively all physicians in town will be part of the same group practice. The reason is that patients will move around. And unless we find a way to build community-based physician self-consciousness as a team, I despair of ultimate success. Share data and share measuring. Therefore when you get this data from Jack Weinberg or Steven Jenks or somebody shows you variations, get curious. Who's the bottom dot? Go find out where there's better information. As an organization. The individual can't do it. The organization has to mobilize the energy to go look at the best somewhere in this country, and I strongly urge you somewhere in the world. The best asthma care in the world is not in America. It is not in America. I suspect the best depression care in the world is not in America. I suspect the best congestive heart failure care is not in America. And I suspect if you can internationalize your searches and organizations you'll find better answers. Get curious about the data. Go to stage four and ask questions about how to change the reality instead of whether to accept the reality. About the environment we are stuck really. We don't have great answers. The best answer we have now technically is capitated payment. The reason is is that once you're able to hand a community a budget for the care of its own population, you get a chance to move the resources around toward the need. Other than capitated payment, other than

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population-based care, I do not know an economic solution to this problem. That's a personal opinion, not a Chasm report conclusion. Prove me wrong. Find another way to sort the money in your community but it will have to result in the ability to move assets from the place where it's wasted to the place where it's useful, even if that crosses an institutional boundary, and without capitative payment to the population level. I don't know quite how to do that. Maybe you could figure that out. Talk to Medicare, talk to Medicaid. Let's get the dialog going. Come up with cost neutral increases and flexibility. That's what you really need. You need Medicare not to give you more money. You need Medicare to give you more flexibility to use the total funds for entering. It would help if we could go to a no fault malpractice system. The Chasm report does not say that. I'm saying that. Eventually the IOM will tackle that issue. We do need to focus all of this on chronic illness care. We picked exactly the right five topics to work on because if we can fix those topics we'd be way, way downstream in terms of designing the care we need. We'll have to listen to Weinberg and Fisher on specialty supply. A lot of the drivers of waste in our community are not because you do not have enough specialists but because you have far too many. So right sizing the community specialty supply is going to be a very, very hard piece of environment. It's going to take everybody with the same vision. It's going to take a totally

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new IT infrastructure and it will include an electronic medical record and registries in your community. There will be no options. It will include public reporting and public measurement of performance at the outcome level, like Jay showed us. It will include a commitment to non-visit care options and freeing healthcare from the notion that we get paid for events instead of for relationships. It will take really careful and respectful shared decision-making methods so that patients are in control, not us. And it will take community-wide agreement on protocol so we can promise you you not only get the same care no matter where you go in Memphis, you will not only get the same care no matter where you go in Kansas City, you will get the best care. It's the same and the best. And that commitment to evidence-based care will cut through the vision. The cross-cutting issues trained for this conference are the same - measurement, information technology development -- and I would emphasize registries and electronic medical records -- financing mechanisms, community activation because this ain't going to happen from within the system. This is not - the system of care lacks the will to do what we just talked about. The will will have to be supplied to it from elsewhere. It will take high levels of cooperation and will take fundamentally new views of the patient, not as the object of our care, not as a guest in our house, but as the host of our work and as the person who ultimately has the say in what we do

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or do not. And the results will be relive those debts, remove those pain or suffering, no unwanted waiting or helplessness or waste. You could tackle it. It's big. I commend you for your courage in starting and I will be with you as long as you wish to help you get through.

DR. REED TUCKSON: That was terrific. We have a few minutes for some burning questions and let me open up the floor for those. There is a microphone in this aisle and a microphone in that aisle, and if there is someone who would like to dig a little deeper on the things that Don has presented or ask for a clarification, please join us. And would you please let us know who you are, sir?

DR. ALBERT GREDNES (misspelled?): Hi, I'm Dr. Albert Grednes from Grand Rapids, Michigan, and first of all let me say as a neurosurgeon, that amen to a lot of this. One of the questions I have is over the past 15 years we've had direct marketing of the pharmaceuticals and device makers to patients, and in many ways they're driving the costs, they're driving what's done. Could you comment on that?

DR. DONALD BERWICK: Yeah, the question is about the facts and I guess my opinions about direct marketing of medications to patients. It's a tough issue. There's no question that direct marketing of medications to patients have net done harm. I have no doubt about that. We are now experiencing levels of overuse, commitment to unnecessary

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medications and complex ones that are a direct result of direct marketing and hurt people. On the other hand I am absolutely - not absolutely, I am more and more close to absolutely coming to think transparency's a non-negotiable issue. We're just going to have to work in daylight. And therefore at that level I must commend direct marketing as a form of transparency. It's going direct to the people that get the medicines and telling them about the medicines. And so, yes, I would not stop direct marketing. I would have a vast social investment in counter-marketing. I believe we have not grappled with the opportunity, the pathway carved by these smart pharmaceuticals to teach us how to help people understand things they need to learn. And we can help the communities understand depression and congestive heart failure and back pain and whatever else we want to work on if we were as serious about social marketing and social information systems as the drug companies are about selling their wares. So, yes, harm done but I don't think transparency's negotiable. And it's sort of like - it's like if you - what's the quote? If you don't believe in the right of someone you disagree with to say something important to you, you don't agree to free speech at all. And I feel that about direct marketing. So, yes, open the doors, let anybody say what they want, but let's provide as a social good information about what kind of care is good.

DR. REED TUCKSON: (Off-mic) the earlier doctor

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(unintelligible) because one of the things we want to do is give you a (unintelligible) 15-minute break (unintelligible) -

DR. DONALD BERWICK: And I'll be quick in my response here.

DR. REED TUCKSON: - (unintelligible).

JOHN GLATSNOSE (misspelled?): I'm John Glatnose from Virginia. (Unintelligible) a talk in which I agree with absolutely everything you say about the delivery of healthcare, but I didn't hear one word about health. The primary issue in American health today is the decline of physical exercise in children and the degree that it impacts three of the diseases we're dealing with is so severe that nothing we do as doctors today is going to have any effect if we don't address it. A type II in children, it doesn't matter how well we deliver insulin. It's got nothing to do with the issue. This disease should not exist and we're doing nothing to do about it.

DR. DONALD BERWICK: I take the point and I apologize for omitting it. The Chasm report does not focus on primary prevention. That was a decision. You need to, of course. I do believe in the chronic care model, which I would urge to be an extraordinarily powerful chartering design frame if you would, is deeply embedded in this and if we could spend an hour on the ICIC (misspelled?) model from Seattle I think we would have to take your question very, very seriously, embed preventative activities directly into it.

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DR. REED TUCKSON: Let me just - I want to just stop for just a moment and respect very much the point that was just made. It is a very important point. In addition to respecting that point I do want us to continue to keep our focus for this particular session on the issues that are in the Chasm and those criteria. And one of the things we understand is and all respect that there are multiple strategies that must be employed in each of these areas, including and especially prevention. So it is an exceedingly important point and I'm glad that you made it. I just want to make sure that we continue to focus our discussion in the afternoon and tomorrow, that we're really laser-like in our effort in terms of this specific agenda, and then we'll marry that, of course, with other agendas as we go forward. Please.

DR. PAUL JARRAS (misspelled?): Dr. Paul Jarras, (unintelligible) in Vermont. Given the scope of the problem and the methodologies and technologies for bringing about change and the inevitable resistance, where do you think the highest leverage points are in terms of focusing our actions to bring about community change?

DR. DONALD BERWICK: What are the highest leverage points to bring about community change? I'm not sure. My first reaction is it depends on the community. Different communities have different structures. The pivotal issues - you can't - nothing - this won't happen without aims. And so

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an absolute key leverage point is a leadership commitment to the improvements we have now put on the screen. And that must be consolidated leadership through coalition structures at the community level. The leaders of your community declaring how good you will get, being transparent while you get there, standing some accountability themselves about whether they get there. That's a don't pass go issue. Getting the physician and clinical force to become excited about this, that is a very, very difficult but important step to take and it will involve some sorting. Some physicians ought not be part of this. They can't be. They don't understand it and they don't - they won't. But invite to create a sense of invitation to the clinicians - clinicians, nurses, pharmacists, respiratory therapists, and others so they're part of the action is a very, very important step to take. The third one is evidence-based. We've got to have community evidence. That's why I'm pounding at you about the ICSI guidelines or about the Wagner model - the ICIC (misspelled?) chronic disease model. Start with the best design of care and don't try to reinvent it. You don't have to do that. You can go to the design. Evidence-based, patient-centered, system-minded (unintelligible).

MALE VOICE: Thank you. I just would like to have a comment about the pharmaceutical industry and its influence on physicians. As a physician we know that the industry is pervasive. It brainwashes physicians into believing that

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ineffective care needs to be provided all of the time.

Basically physicians have become prostitutes for the pharmaceutical industry and unless we do something about this pervasive influence I don't see how we're going to change this. It's something we have to address.

DR. DONALD BERWICK: There are many barriers, A.J. The pharmaceutical industry is one voice. Supply another. Give another story. Help patients understand as a community what best care really looks like and they finally - they will have an alternative. But I think that saying - the only word - I agree with every word you said except unless. Because the minute any of us puts a trump on the table and says unless this changes we can't do this, we're dead. Because not everything will change. We're not under our control. Yes, I wish the pharmaceuticals would act differently and I think maybe ultimately they will if it's in their self-interest (unintelligible) the Chasm report. But don't make it an unless. It's an and. And I wish the malpractice situation would change and I wish the financial system would change, but I'm not going to wait for any of them. My action plan is under my control.

JERRY ANDERSON: Jerry Anderson, Johns Hopkins University. My question is what's your message to the 200,000 physicians in training? Is this - next week I'm going to start teaching the Johns Hopkins medical students pretty much the

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same material. I've done it for ten years. They get it after a while and then they say, but you're training me in a program into a system that doesn't work. You know, and then they get very dishearted (sic) and then they give up on me. So I'm trying to figure out, what's the message?

DR. DONALD BERWICK: Thanks. What a wonderful challenge. It's essential. And in fact I've changed my song on this. I believe that young people entering our profession -- not just physicians -- nurses, pharmacists -- are so ready for this. So ready and so willing. They're a different generation. They don't have a habit. Don't necessarily have the myths. They haven't been taught them yet. And so I find them the best audiences. And I wonder if with leaders like you and energy like theirs, you can work the revolution together. Actually you're co-changing. And the answer to that person is a, hi, you're right. You go back into that system unarmed with the intention to change it. And unarmed with the help I'm going to give you. You will be battered down but we're not going to let that happen. So we're going to have young/old, young/small revolution together. And I think the potential for change through new education is much higher than I would have thought a couple years ago. I'm very, very inspired by working with young people around this message. So I commend you for continuing it and I think maybe some support system after they enter a world that they're scared of would help them (off-mic).

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DR. REED TUCKSON: (Off-mic) because we've got one minute. Let me (off-mic).

FEMALE VOICE: Just a quick - (off-mic). Don, you made me think about - you said - you talked about true north and made me think about the difficulty of actually bringing forth (off-mic) solutions to the problems that have been enumerated in the report so effectively. The question I guess to you (off-mic) is probably a rhetorical question at this point. Isn't there a role for the IOM in terms of - you talked about transparency (unintelligible) or do we just skip over in this discussion the reluctance to disclose, to shed light, all the issues we've talked about. What - isn't there a role for the IOM in (unintelligible) taking the next step in a three-year-old report to enumerate what is in fact true north? If we wanted to bring this together at a community level what could we do? How would we go about doing it? What are the set of reluctances? And the thing that I think is a useful cautionary tale, our health plans were looking (unintelligible) evidence-based as a standard by using -- and I'll use the words very specifically -- utilization review techniques, which people didn't like. They didn't like them because we were beginning to shrink expenditures out of the system. So how do we not reinvent that? That disquieting resolve in various communities around the country? But I think to go and (unintelligible) and think that we're going to be facing these structural problems,

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systemic problems at the local level, not think about a way that at the national level very good people, good spirit, could come together to shed some light on how we do this (unintelligible).

DR. REED TUCKSON: Let me just say that it is a wonderful way to, Karen, to serve as a challenge and a focus for in fact the afternoon's work and the work of tomorrow morning. So I would - unless Don wants to make a specific comment, I would like to leave that squarely in front of the subcommittees and the sub-work that's about to begin in about another 15 minutes. So I couldn't thank you more for teeing it up just as well as you did. Last comment, please.

FEMALE VOICE: Just a quick question. Could you comment on the - how the Stark amendment and all its loopholes might contribute to overuse of procedures, et cetera? And if there's anything in the future to - if anybody's going to be looking at this again.

DR. DONALD BERWICK: The cause of the suspicion in public about the withholding of necessary care, the policy agenda is just to make sure that under-use doesn't happen and therefore we overshot our policy. Neither the public nor the Congress understands the physical toll - psychological and physical toll of overuse of care and I think we have a very important educational effort to undertake. And I wouldn't - I don't know how to deal with it at Congressional levels, or with

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the Stark amendment. I believe at the community level we could have communities in this county that understand that too much is bad, more is not better. We have Sal Amorga (misspelled?) and it's use of end of life care is world class. Best in the country maybe, and they do it and the community understands that doing more is worse care. And I think we can do that at the community level. That's my only - the only daylight I can offer.

DR. REED TUCKSON: Would you please thank Don Berwick again? You have been a wonderful and patient audience. I have got to quickly give you a couple of pieces of information and let you have a break and then go to the working lunch. The working lunch starts at 11:45. The working lunch is basically a meet and greet for you to meet the people that are in your specific disease and condition specific groups. How do you know where to go? You have a passport in your packet. Please do not decide that you're going to change groups because we have ballenced these groups through a very complex calculus and quantum mechanic theory that is specifically designed to have you in the right place. So if you go to the wrong place you screw the whole thing up. Number three. You will have your meet and greet and you'll eat and you'll relax at 11:45 and there are, by the way, people around who will show you where the boardroom and room 150 is and so forth. You will not get lost. Trust us. Then from that we will go at 12:45 to these

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crosscutting strategy sessions. Each of you is assigned to two of those sessions. They will go in sequence and there is very little transition time from room to room. The facilitators, whom I want to thank immensely for their leadership and their skill, will make sure that they end their sessions on time to get you to your next room. Don has well laid out what we're trying to do with the crosscutting strategy sessions. These are to set the tools that are necessary to begin to move this agenda forward generically and then of course which are applicable to each of the specific disease conditions. As we leave from that we will then at 4:00 begin to work in our specific conditions, specific groups, and then the facilitators of those groups will give you a good sense of what you're trying to accomplish, how you will identify the key barriers, how you identify the strategies, and the redesign that Don specifically talked about. I will keep my comments to those. Only one other plea. The key to all these sessions, if they're going to work, is keep your - is to listen, listen, listen, keep your mind open to new ideas, and then to contribute as well as you can. We've tried to engineer these sessions to be as efficient as possible. This is where that commercial I gave you earlier applies. If things don't go real smooth and the conversation is jutting and starting, forgive, forgive, forgive. But at the end of the day we're all in this boat together. We look forward to rowing with you. Have a good

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1/06/04**

127

working lunch and thank you so much.

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