Transcript
Partnering with Patients, Families, and Communities: An Urgent Imperative for Health Care
2014 Macy Conference Recommendations

Moderator:

Good day everyone, and welcome to the *Partnering with Patients, Families and Communities to Link Interprofessional Practice and Education* webinar. Today's conference is being recorded. At this time, I would like to turn the call over to Dr. George Thibault. Please go ahead.

Dr. George Thibault:

Welcome everybody. I'm George Thibault, President of the Josiah Macy Jr. Foundation, and we're very gratified by the high level of interest in the recent conference sponsored by the Macy Foundation and the recommendations of which were published in June of this year. And a full monograph from that conference will be published in September.

At the conference, 42 conferees came together and these included patients, leaders of patient advocacy organizations, health care educators and leaders of health care organizations from diverse institutions nationally and internationally. The full list of participants is available on our website. But I would say it was an unusual gathering that cut across many different sectors, and many people commented that rarely have these groups been represented in the same room at the same time, with a united and common purpose of coming up with consensus recommendations. Prior to the conference, a commission paper was written to lay out a vision for where this conference should go, and four case studies were commissioned to provide material for discussion. We then underwent three days of structured discussion in both plenary sessions and breakout groups leading to the consensus recommendations that we will talk about today. The recommendations that came from the conference were refined by the Planning Committee with further input from the conferees.

I should note before I go on to talk a little bit about the substance of the conference, that the discussion that we're starting here today in the webinar can be continued afterwards on Twitter using the hashtag #PatientsAsPartners.

The motivation for the conference was our continued response to the momentous changes going on in the health care system in the United States and our belief that education reform is absolutely necessary to prepare a workforce for a changed health care system. That, in fact, we will not have enduring health care reform unless we rethink how we train health professionals to work together and to work with the patients and communities that we serve. There is an urgent need to link delivery reform in education reform, and this was the subject of the Macy Conference that was held in January 2013.

And from that conference in which we examined with leaders of the education system and of the delivery system how we could bring the two worlds closer together, we came to a realization that the essential link to do that were the patients and families and communities, and that we must welcome them at the table as actual partners working collaboratively with all concerns to set agendas, to determine policies and priorities, and to make decisions and to help implement them for both health professions education and healthcare delivery.

Partnering with patients, families, and communities requires a fundamental cultural shift in traditional health professions education, in clinical practice, and in patient participation. The conferees stated their vision for the conference results that we envision a future in which individuals, families, and communities are understood to be the very reason our health care system exists and that those who are caring, teaching, learning, or otherwise working within the system must partner fully and effectively with them to foster optimal health and wellness for all.

So with that as an introduction framing why we had the conference and what the ambition vision was for the conference and who participated, I'm going to ask our two distinguished co-chairs who so ably led the conference to take you through the recommendations that were made by the conferees, and I stress that these were consensus recommendations from all of the participants. Terry Fulmer, PhD, RN is professor and Dean of the Bouve School of Health Sciences and Professor of Public Policy and Urban Affairs in the College of Social Sciences and Humanities, all at Northeastern University in Boston. Martha Meg Gaines J.D., LL.M is founding director of the Interdisciplinary Center for Patient Partnerships at the University of Wisconsin in Madison. She's clinical professor and Associate Dean of Academic Affairs in Experiential Learning at the University of Wisconsin Law School. Terry, we lead off.

Dr. Terry Fulmer:

Thank you Dr. Thibault. Let me just say what a privilege it's been to co-chair with Meg and also to participate in this extraordinary conference. It is my pleasure to open with a review of the first two recommendations. Just before I comment on recommendation one, I'd like to set the stage for the way we began our conference. The evening before we began, we joined in a very lovely communal dinner, but the most important part of that dinner is that we invited two very special patients who came to us and spoke with us about their lived experience. So, let me just comment for a minute about that, and if you're looking at your materials, you'll know that the stories are so incredibly poignant.

One is a story of a very fascinating man who has set the charge for his country, Norway, to tell them what he needs for his dialysis. And to say that his experience has been, he told us about his experience, how he had become ill, and with his failing kidney health, he learned that what was most important for him was to take charge and to be able to go to dialysis with his own key, set it up, get there when he wanted on his own terms. It was riveting to listen to the way that minds began to shift in that room as we thought about, well, how are we patient-centered?

Then we heard from an individual who told us his story about being wounded, almost fatally, by a gunshot by his best friend who accidentally shot him and wounded him in a way that left him in a wheelchair, paralyzed to this day. We heard how he characterized that as one of the luckiest days of his life, as he told us about his story and some of the very dangerous neighborhoods in which he grew up.

So, that really sets the stage for us to talk about our recommendations and to really, really focus. I give that to you as the context for the way that we began our program. Let's talk about recommendation one.

Our very first recommendation is that we must make changes in the content and conduct of health professions education necessary to graduate practitioners who partner with patients, families, and communities. That is a very tall message. And what we know is that we've got a great deal of work to do.

We have to develop a competency framework focused on building effective partnerships with patients, families, and communities. We have to develop a framework for educating patients, families, and communities about effective participation in classrooms and other settings and about serving as co-educators of health professions students. Further, we have to develop comprehensive faculty development programs focused on teaching health profession students how to build and sustain effective partnerships with patients, families and communities, which is no small order. And finally in that recommendation, we must design and teach both coursework and experiential offerings in the institutions that educate health professionals to produce an effective partnership competencies mentioned above.

Our next recommendation is to make changes in health professions education organizations and health care organizations themselves necessary to facilitate durable partnerships, both new and existing with patients, families, and communities.

And therein thinking about how leaders of both health care and health professions education must create new visions and mission statements and operational processes that meaningfully incorporate patients, families, and communities. And also that the governance of organizations involved in the transformation ranging from local health providers to large multi-organizational systems and schools for the educational health professionals should be fundamentally restructured to integrate the principles of partnership.

Finally, in that recommendation, leaders in health care and health professions education organizations should commit to preparing all team members, faculty, clinicians, direct health care workers, students and patients, families, and communities to partner in co-creating educational curricula and optimal health care.

I want to go back and just comment on one more element of our recommendation one. We proposed that we need to convene a national group of stakeholders to develop measures including structure, process, and outcome measures that institutions that educate health professionals can use to assess their performance in integrating partnerships in their curricula, develop a research and evaluation agenda, and work with accrediting agencies for health professions education and certification organizations so that we can make this all a reality. Very exciting conversations. Let's turn now to Meg.

Martha Meg Gaines:

Hi everyone, and thanks to the Macy Foundation and all the staff and Dr. Thibault and to Terry for a remarkable experience. Recommendation three focuses on building capacity for partnerships both among patients, families and communities and among health professions, educators and health care organizations. The overall overarching points of this recommendation are that partnering with patients, families, and communities is mission-critical to successful health care from the individual clinical level to the organizational reform level and to the national reform levels. And that patients, families, and communities have to be involved in all of those. Not because it's polite or thoughtful or kind, but because patients, families, and communities have information that is mission-critical to success of effective healthcare services and effective health care systems. We talked about lay knowledge at the conference, which is knowledge people have about their own bodies, their own values, their own daily lives, the things they do and don't want from health care. And that that is information that's been missing for too long from the health care conversation, right from the clinic level all the way up to the national public discernment about the future of health care.

The second major point of recommendation three is that there are old assumptions hanging around both with clinicians about patients, families and communities and about their own roles, clinicians' own roles, and what's an appropriate role for a particular clinician to play. And there are also assumptions held by patients, families and communities about clinicians, what their jobs are and are not, and about our own roles in health care and responsibilities and that those assumptions need to be reevaluated and recalibrated. The third major point of recommendation three is that there are a few important efforts already shaping things and that the recommendations strongly advise the need to connect these efforts and to engage leadership at the health care organization level. So, leaders in health care organizations, leaders in consumer groups, and an overarching national structure. Leadership at the national level to help create capacity-building infrastructure. And when I say capacity building, I mean building the capacity for both patients, families, and communities, and for health care professionals and organizations to partner effectively together. That's going to require some learning about each other.

Recommendation four: Make regulatory and payment reforms that require support and sustain partnerships among patients, families, and communities and health professions education and health care organizations. I think this recommendation mainly makes the point that we need to capitalize on the timing of health care reform, the Affordable Care Act, and to embed partnership, the infrastructure to define, create, and support partnerships with patients, families, and communities. First, in some sort of low hanging places, potentially the Centers for Medicare and Medicaid Services and in particular the Center for Medicare and Medicaid Innovation are places where we can, in a regulatory capacity, we can embed partnership infrastructure and support. Also, we can integrate partnership requirements and expectations into the financial support structures for graduate medical education and graduate health care education broadly and embed those requirements into accreditation, certification, and maintenance of certification across the professions.

In order to make sure that what's getting embedded and is something that people are on board with across the professions and the patients, families and communities, we recommend that someone convene a summit of major accreditors, education leaders, clinicians and patients, families and communities to produce a framework and a position statement that launches and guides an action plan based on a commitment for incorporating partnerships with patients, families and communities into those certification accreditation infrastructures where it's most likely to be sustained.

So I think overall, just a couple of quick observation in closing and then we'll open it up for questions is that it was phenomenal for me to see a patient advocate and a patient and someone who trains advocates. It was phenomenal for me to see people come from such different walks of life, from such different places, from such different incentive spots within the system. And really it became very clear very quickly, partly because of, as Terry said, the context in which I think we opened and launched the meeting that there was never any real difficulty, never any real confusion about whether everyone was 100% behind the concept. Any sort of back and forth conversations we had in our small groups and our recommendation groups was about how, not about whether. And I think that's a powerful moment in our health care system's life or in its trajectory. And I think the ability to capitalize it on it through the Macy Foundation recommendations is awesome, as Mike had said.

Dr. George Thibault:

Thank you, Terry and Meg. Those were excellent summaries and also insights to share with our audience. We are open now for questions. I will try to be sure I understand the question and then triage the question to Meg or Terry or myself. We have a queue for the questions, and we will start now.

Moderator:

Thank you very much. If you would like to ask a question over the phone lines, please press star one on your telephone keypad. If you're using a speakerphone, please make sure your mute function is turned off to a ladder signal to reach our equipment. Once again, if you have a question at this time, please press star one. We'll pause for just a moment. We'll take our first question from Alexa Miller with Arts Practica.

Alexa Miller:

Hi there, can you hear me?

Dr. George Thibault:

Yes.

Alexa Miller:

Hi. Thanks for this webinar. I'm really curious about the education piece of this, and I was wondering if you could talk more about some of the skills and capacities that you are hoping to nurture in trainees across disciplines to make them more susceptible and inclined to partner?

Dr. George Thibault:

Terry, do you want to take the first crack at that?

Dr. Terry Fulmer:

I'd be happy to, George. It's a complex and important question. If we could put it into components, I think you're talking about where to begin, what the incentives will be and how we'll know. Is that correct?

Alexa Miller:

Yeah, definitely. And I'm also curious on a more granular level, just within the development of student skills, if you have a sense at this point of what some of those skills and dispositions are?

Dr. Terry Fulmer:

Well, we believe, and you may have seen our monograph, that there's a real partnership sweet spot that comes among the health professions education reform movement, patients and families in clinical practice reform. It's within that nexus that we believe that we have to be developing and designing the courses in experiential offerings. We've seen examples of how high-fidelity simulation can make a difference in avatars even, and the way that patients come in and work with us in our curricula come to our classrooms or we go to their world in order to do the teaching makes a difference. What we now have to do is develop a research and evaluation agenda to see what's working. And the most important question is what are we seeing that's fundamentally different? So we have phases to go through. And I think that what I would add is the following.

There's a lot of content that's out there for us to build from. We have over 30, 40 years of the geriatric education center initiatives. We have the work of the Hartford Foundation, we have the geriatric interdisciplinary team training programs, the work of the VAs and the new National Center in Minnesota. What we have to do is collect the content, make sure there's patient embeddedness, and then go ahead and see if our students are fundamentally taught differently and ask our partners in the clinical practice reform if they're seeing a difference. So the answer is we're on the road and at the granular level, we're looking for the data.

Dr. George Thibault:

So that's an excellent answer. I would just add to that, to the questioner, who I take it as probably an educator, that we need to heighten the efforts we're already putting into communication skills, teamwork skills, but add to that understanding about the limitations that we have both as individuals and systems, that is a humility. The use of appreciative inquiry, an increased community awareness, which we believe can only come by having parts of the training actually in the community. We believe that the efforts that we've already put into interprofessional education create a wonderful model for the kind of attitudes and behaviors that health professionals will need if they're going to go beyond even the circle of working together as health professionals to working with other people in the community. But we think that behavior gets modeled by the interprofessional model.

Finally, and fundamentally, we are talking about a culture change, a real difference in the culture of the health care system and its educational components that not only treats everybody with respect and honors the value that everybody brings to the table, but not only says that, but actually lives that. So that would be my answer to your question as you think about both the components of an educational program and the environment in which that program needs to exist.

Martha Meg Gaines:

George, I would just add to what you said, a respect for the expertise or really an ability to see that what patients, families, and communities bring is an expertise, which is the that without which, right? It's hard because we have to understand that having functioned without it is really problematic, but what we can do about that is to understand that and to see how much better it gets. Terry's reference to the dialysis of the patient, Chris John, with his own dialysis is a perfect example of how beginning to respect that expertise is a very compelling draw to professionals changing the way they practice.

I also think an understanding of the health care system, how it's financed and how it's administered is a very important skill to make sure health professionals have. As well as more training on the ability to understand the lives of people who, for lack of a better word, consume health care. What's going to happen at home? How is this going to work back where you come from?

Dr. George Thibault:

So, good question, ready for our next question.

Moderator:

And as a reminder, please press star one. We'll take our next question from Mary Anne Kane Breschi From Maggie's Light Foundation.

Mary Anne Kane Breschi:

Hi. I'd like to say thank you for this conference as well. This just speaks so much to my heart. I am a parent of a young woman with multiple disabilities and complex medical needs living here in Maryland, and I co-founded and am Executive Director of the Maggie's Light Foundation, and we have a program in which we call Community Works. Through Community Works, I do about 25 to 38 presentations a year during the academic year to undergrad and graduate students at Johns Hopkins, University of Maryland, George Washington University students studying in fields related to disability or health. And the presentation is all about the family perspective. Our point of view is that for young men and women going into the field, you really need to understand the whole picture if you're really going to be successful in bringing about the health outcomes that you intend to bring about.

So, my question is this: We have some data working with the Maryland Center for Developmental Disabilities out of Kennedy Krieger. I actually don't even know what my question is. There's just so much going through my mind. And how do we partner with you? Is there funding available? Is there funding to convene the symposium that you'd like to convene? And just those kinds of questions. How do we become a part of this on a national level, I guess is what I'm asking?

Dr. George Thibault:

Meg, do you want to take a crack at that? And then I will follow. Did I lose Meg.

Mary Anne Kane Breschi:

Mary Anne's still here. I don't hear anyone else speaking. No.

Dr. George Thibault:

Meg? Well, I hope Meg will get back on. Well, so your question is a good one, and it's a question we are all asking ourselves coming out of the conference, how can we build on this momentum? Obviously, there are a number of organizations that already exist, such as your own, and such as several that were represented at our conference including Bev Johnson at the Institute for Patient and Family-Centered Care, and Deborah Ness at the National Women's Partnership. So, we're hoping that those existing organizations will increasingly work together and work with physician groups, we were very encouraged that the head of the American College of Physicians just published a paper in the Annals with Deborah Ness and Bev Johnson. So the largest of the physicians specialty organizations in the country is getting on board.

Mary Anne Kane Breschi:

Terrific.

Dr. George Thibault:

So we are hoping that more and more partnerships such as this will help to create this momentum and there will be moments for the Macy Foundation and other foundations to step in to help catalyze this, but we think it has to be a multi-pronged effort to get more and more organizations focused on this. Meg, did I hear you rejoin us?

Martha Meg Gaines:

Yes. Sorry, I don't know how, but I lost you or you lost me or something. Yeah, I would concur with what you said, George, and point out that we did recommend some kind of a national summit, I think, to talk about the specific questions about how to embed the partnership values that the last caller asked about and the partnership skills into the accreditation and maintenance of certification and certification procedures. So I think that's another arm of this that will be active going forward. I think another national kind of meeting where we define precisely the partnership skills and the gaps and the training curricula and pedagogies available to help fill those gaps would be another, I think, very important process. And I know Barbara Brant and folks at the Minnesota Center would very much be interested in further talk about that.

Dr. George Thibault:

Very good question. Next question?

Moderator:

We'll take our next question from LaQuanta Smalley from US Department of Health and Human Services.

LaQuanta Smalley:

Good afternoon everyone. I have a general comment as well as an offer. Of course, my name is Laquanta Smalley and I did not see my agency on the list of participants, unfortunately, but I lead the Family Professional Partnerships program within HRSA's Maternal and Child Health Bureau. So you all are talking, you all are definitely speaking our language, specifically around parents and families partnering with providers as it relates to children with special health care needs.

Now I want to thank you all for compiling this information, first and foremost. And secondly, I'm just interested in what are the next steps that you all are preparing for? And in those next steps, I want to offer myself as a resource to help push this forward because this is definitely a passion of mine considering my role here in my agency. I know that my bureau and my agency also prioritizes having this type of partnering between families and providers as well. We say families because we deal with children, but we understand that that also means patients as well. So if you all are convening a group in the future, I want to offer myself and my organization because we have a plethora of tools and resources, we have a data set in the National Survey for Children with Special Healthcare Needs that we can offer. And I'm just making myself available to you all.

Dr. George Thibault:

Well, we thank you for that and we would love to follow up. And if you can send us an email, we would love to follow up with you. We have been working with HRSA and Freddy Chen, who's been a special consultant to HRSA, was in attendance at our meeting. HRSA, as you probably know, is the federal sponsor for the National Center for Interprofessional Practice in Education in Minnesota that is also being supported by us and three other private foundations. So we have worked closely with HRSA and we're very aware that there's great synergy between HRSA's goals and ours. We're happy to add you to our list of HRSA contacts.

LaQuanta Smalley:

Thank you.

Martha Meg Gaines:

George, can I use that question just to say one other thing that I thought was really important.

Dr. George Thibault:

Yes, please.

Martha Meg Gaines:

I sort of take it from the comment and the offer. One of the things that was really hard for us as a planning team, and I think was important at the conference, was that we kept a distinction between, and not in terms of importance, but just a distinction in terms of talking about the difference between engaging patients, families, and communities in their own care, engaging patients, families, and community in the reform or the changing of organizations, that's clinics, hospitals, local health departments, that kind of thing. And then engaging patients, families and communities in national or local, statewide, whatever reform efforts in broader policy and system reform efforts. It's important, I think, to us to have those distinctions and make sure we're sort of firing on all those cylinders in terms of pushing this forward.

I'd add one other thing. We had a paper in preparation for the conference prepared by Angela Coulter, who's from Oxford and is a British scholar, and Michael Berry, who's from Boston, and is a US physician and scholar. We had some fascinating conversations about the difference between the United Kingdom and the United States being that in the United States, patients are having an easier time getting proactive and partnering in their own care, but still are not as involved or as active partners in the two more meta levels of engagement. In England, it's the opposite. Patients and family members and communities have been more interested in being involved in talking about the policy and philosophical questions around meta delivery issues, but are still quite timid about being engaged in their own care.

I don't know what to make of that except that I think generally speaking, the ability to partner starts somewhere, either with someone getting interested in a PFAC, a patient family advisory committee at a hospital or getting asked to be on a committee or something like that. Or as in one of the previous callers when you have a family member, and you start by being a really assertive and proactive consumer of health care services. But it is an interesting distinction to make and I think an important one for us to be aware of moving forward on all levels.

Dr. Terry Fulmer:

Meg, it's Terry, and I couldn't agree with you more and would add that our experience from a patient from Sweden where taking that step, having the hospital really work hand in hand, making it a national movement, we know it can happen and we need to see more of it here.

Dr. George Thibault:

Okay, good question and good offer. Thank you. We're ready for the next question.

Moderator:

As a reminder, it's star one if you'd like to ask a question. We'll go next to Rachel Grob from the Center for Patient Partnerships. And Ms. Grob, we're unable to hear you. You might try picking up your handset or pressing your mute button.

Rachel Grob:

Sorry about that. Can you hear me now?

Dr. George Thibault:

Yes.

Rachel Grob:

Okay. So thank you for a very informative webinar and a very useful report. I'm wondering if you can give a little bit more detail about the capacity building that you discussed with respect to patients, and particularly picking up on the point that you just made, Meg, about the difference between capacity in the UK and in the US for engaging at the system level in policy, program-building, and philosophy. What does it take for patients to be ready to do that? And what kinds of examples did you see, nascent or fully bloomed, in the US that we can build on here?

Dr. George Thibault:

Meg, go ahead.

Martha Meg Gaines:

Well, this is a complicated question and I guess I'd start off with, like all lawyers, with a caveat saying this was a complex set of issues we addressed at the conference, so we didn't go deeply into this one. But we were well aware that it was important to go deeply into this one, both with respect to competencies in patients, families, and communities, and with respect to competencies for partnership in health care professionals. But the stab I would take at the answer to your question is, first of all, we believed it was important for patients, families, and communities to be welcomed and to feel invited into partnership. So in order for that to happen, I mean it's a little catch-22, but in order for that to happen, we actually have to have health care professionals, leaders, a combination of carrot and stick, if you will, to make the presumption or the bottom line the default that we cannot proceed without informed patients, families, and communities involved in these critical conversations. So that's turning an aircraft carrier, that's a tectonic shift in attitude, shift in awareness, shift in appreciation.

Education being one of the big ones and leadership both at the organizational level being another one and at the national level, and particularly taking advantage of the incentives and of the opportunities for change that recent sort of health care reform has engendered. I think we left it vague kind of on purpose. Who would convene what summit because I think we want to hear precisely from folks on this call and others who react to this, what they're up to. We didn't assume we had all the information about what everybody was doing at the table, and who might be interested in convening these kinds of summits.

But again, I go back to the fact that one of the things that I think blew me away at a really low, deep level was that there wasn't any question from anyone. Maybe folks didn't feel safe to say it, but I doubt it. They felt pretty good saying whatever. There wasn't really much pushback from anybody about the importance of doing this, the awkwardness about the fact that we haven't done it thus far and the need to do more of it. I guess I'd say the last thing is with respect to patients, families, and communities developing these skills, I do think it sometimes starts with people doing it at a philosophical or a policy level and translates into how they are able to advocate for themselves and their loved ones in the clinic and hospital setting. And sometimes it goes the other way.

Dr. George Thibault:

Good answer to a good question. We have time for a couple more questions.

Moderator:

And as a reminder, it's star one if you would like to ask a question. At this time, we have no further questions in the phone queue.

Oh, we do have a follow-up from Mary Anne Kane Breschi from Maggie's Light Foundation.

Dr. George Thibault:

Okay.

Mary Anne Kane Breschi:

Hi. Just a quick question. How will I be able to follow your activities? By mere fact of having joined in this webinar, will I automatically receive information regarding your activities? Will all of us receive it?

Yasmine Legendre:

You will receive a follow-up email letting you know on our slides and it's available on the website. And you are welcome to join our mailing list. Also, if you want to send me, Yasmine Legendre, a quick email, I can happily add you to our mailing list and you can be updated on sort of our activities. But I would also suggest to monitor our website as we do postings there fairly regularly. You can also join us on our LinkedIn group, the Josiah Macy Jr. Foundation.

Dr. George Thibault:

I want to thank everybody for their interest in participating in the webinar, and I want to particularly thank our co-chairs, Terry and Meg, for not only the great job they did on the webinar, but the leadership that they showed prior to the conference and during the conference, and in the writing of the report. Remind everybody that the recommendations that you saw presented are available on our website. You also can get the full listing of everybody who participated in the conference to maybe give you ideas of others that you'd want to contact who share in these beliefs. In addition to what we may do at a national level and help catalyze at a national level, a lot of this activity will be local activity. So for those interested, finding your local partners is what I would strongly recommend. I think that the strength of this movement will be very much due to local activity where people find their partners in their own neighborhoods.

We will continue to think about our own response as the Macy Foundation, as we prioritize our spending going forward for conferences and for grants. We will continue to look for others to partner with across the spectrum of patient organizations, educational organizations, health care delivery organizations, and health professional organizations. So we think that this is very, very critical at this point in time and actually is a good point in time. For all of the concern about health care in this country, I think the changes going on have created an environment in which this kind of message is more likely to be received and where there are more opportunities now to bring about the kind of cultural change that we're talking about.

So thank you all for your interest. We ask each of you to think about what you can do locally in your own institution, in your own organization, who you can partner with to fulfill this. And we hope to have you involved in our conversations going forward.