



# CONFERENCE RECOMMENDATIONS

April 3 – 6, 2014 | Arlington, Virginia

## Partnering with Patients, Families, and Communities: An Urgent Imperative for Health Care

Recommendations from the Macy Foundation Conference on Partnering with Patients, Families, and Communities to Link Interprofessional Practice and Education

In April 2014, the Josiah Macy Jr. Foundation convened a meeting whose purpose many participants described as unprecedented. It brought together patients, leaders of patient advocacy organizations, healthcare educators, and leaders of healthcare organizations to make recommendations for the urgent reform of both health professions education and healthcare practice in partnership with patients, families, and communities.

As one participant summed up the conference: “We’re spending so much time these days talking about fixing, reforming, transforming, even revolutionizing the American healthcare system. But what we’re really talking about is turning it right side up and placing the focus where it should have been all along: on the patients.”

In addition to the recommendations for transformative action contained in this conference summary, conferees also crafted and agreed to a vision statement for health professions education and healthcare practice going forward. The statement reads:

*We envision a future in which individuals, families, and communities are understood to be the very reason our healthcare 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.*

The vision statement purposefully uses the verb “partner” in place of “engage” (which was the original word used by the Macy Foundation when

planning the conference). The conferees agreed that patients, families, and communities<sup>1</sup> must be welcomed to the table as equal partners, working collaboratively with all concerned to set agendas, determine policies and priorities, and make decisions and help implement them. Further, the wisdom of patients, families, and communities—gained from their experiences—must be recognized to be as important as professional expertise in these partnerships.

In developing the vision statement, conferees recognized that partnering with patients, families, and communities requires a fundamental cultural shift in traditional health professions education and clinical practice. This shift, which conferees believe is urgently needed, may be both uncomfortable and transformative because it involves moving beyond the realm of personal care decisions, consumer focus groups, satisfaction surveys, and community meetings. It is about equal, respectful, and mutually beneficial partnership at every level and in every health-related endeavor, from designing educational curricula to setting research priorities to hiring faculty and leadership to operating healthcare organizations, and much more. It is about co-creating optimal health and health care.

These changes must start immediately, and will require many years of sustained effort to become part of the culture of health professions education and health care. Conferees believe that pursuing this vision now not only is the right thing to do, but also will lead to improved quality, efficiency, and functioning within the healthcare system and to better health outcomes for all of us. They further caution that failure to partner in this way will lead to continued disintegration of health professions education and clinical practice.

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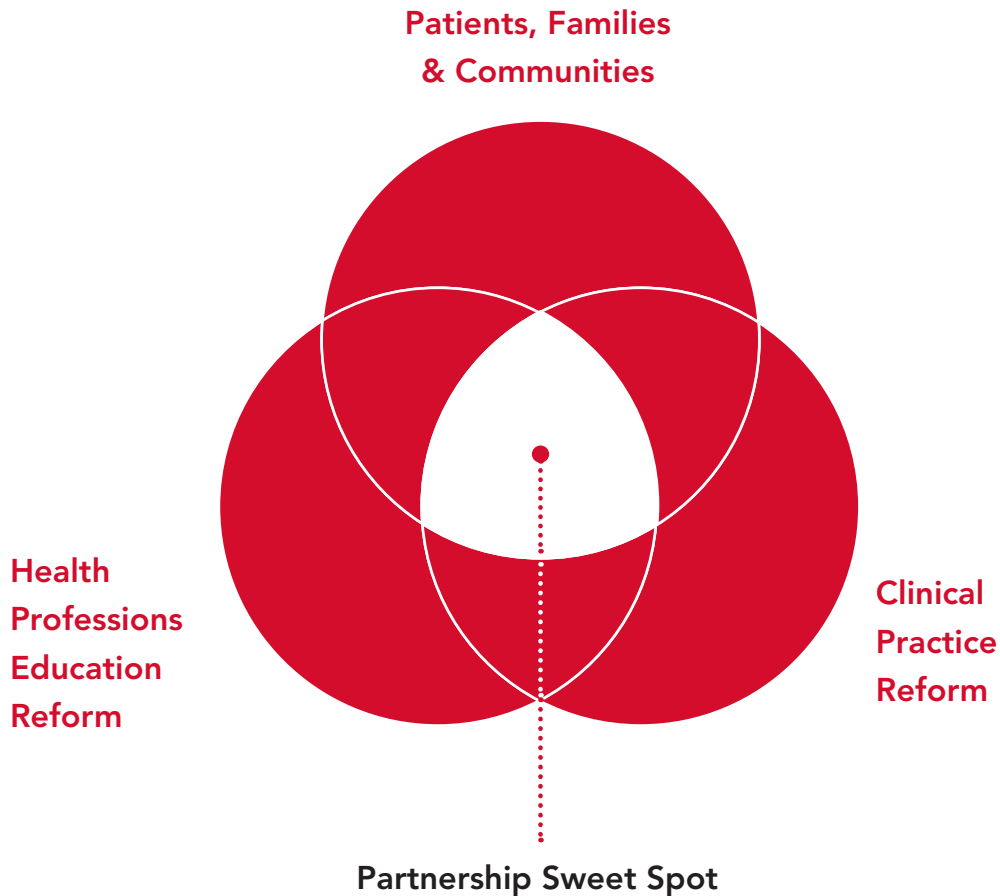
<sup>1</sup> “Patients, families, and communities” are defined as those people or groups of people whom the healthcare system serves, supports, and collaborates with to co-create optimal health and health care.

## The Story Behind This Conference

We can trace the philosophical roots of this conference back to at least September 1978 and the historic International Conference on Primary Health Care, held in Alma Ata (in today’s Kazakhstan). A landmark declaration from that global meeting was, “The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.”

Unfortunately, 36 years later, the American healthcare system still wrestles with—and, until recently, largely resisted—the meaningful participation of patients, families, and communities in co-creating optimal health and health care. In spite of efforts by patient advocacy groups—such as the National Patient Safety Foundation, which declares, “nothing about me without me”—little progress has been made toward truly integrating patients’ voices into the reform of health professions education or clinical practice.

We now have an opportunity not only to honor the Alma Ata declaration, but also to update it, recognizing that the “duty” to participate in the planning and implementation of health care belongs to all partners—patients, families, communities, and all who work, teach, and learn in the healthcare system—equally. Not only that, but we now know that health has much less to do with health care and much more to do with the myriad factors in our lives that affect our health—from the safety of our neighborhoods and our access to healthy foods to the quality of our schools, the job opportunities of our workers, and the affordability of our housing. We now understand that the partnerships needed to create optimal health for all must reach beyond the walls of our hospitals, community clinics, clinicians’ offices, and health professions schools into our communities, neighborhoods, and homes.



The Josiah Macy Jr. Foundation has been involved for many years in seeding and supporting innovations in health professions education, with a focus on turning out healthcare professionals who have a much broader view of health and wellness. These innovations involve teaching health professions students to work together in interprofessional teams and teaching them to coordinate care over time and meet a broad array of needs among increasingly diverse patients, who receive care in a variety of settings.

More recently, the Macy Foundation has come to recognize the need to link the reforms it supports in health professions education

to the reforms that are well underway in clinical practice, which are focused on team-based, patient-centered care and population health. Historically, there has been too little connection between interprofessional education reform and clinical practice redesign. In January 2013, the Foundation hosted a conference to help bring the two realms together so that practice redesign can both inform educational reforms and embrace an educational mission.

One of the five recommendations from that conference was to “Engage patients, families, and communities in the design, implementation, improvement, and evaluation

of efforts to link interprofessional education and collaborative practice.” There was a clear consensus among conference participants that patients, families, and communities should be partners from the start in the effort to create an interprofessional education and care continuum that meets the needs of the public. This is the partnership “sweet spot” shown in the accompanying diagram. That recommendation led directly, in April 2014, to the Macy Foundation conference on “Partnering with Patients, Families, and Communities to Link Interprofessional Practice and Education.”

## Recommendations from Conference on Partnering with Patients, Families, and Communities to Link Interprofessional Practice and Education

Conference participants crafted recommendations in four areas focused on fostering partnerships among patients, families, communities, and health professions education and clinical practice organizations. They are:

1. Make changes in the content and conduct of health professions education necessary to graduate practitioners who partner with patients, families, and communities.
2. Make changes in health professions education organizations and healthcare organizations necessary to facilitate durable partnerships, both new and existing, with patients, families, and communities.
3. Build the capacity for partnerships among patients, families, and communities and health professions education and healthcare organizations.

4. Make regulatory and payment reforms that require, support, and sustain partnerships among patients, families, and communities and health professions education and healthcare organizations.

These recommendations are described more fully below, including specific actions for implementing them. And, while the recommendations are presented as a numbered list, they are interdependent and of equal importance; no single recommendation takes precedence. Many other important ideas for improving patient and family engagement in health professions education and clinical practice were raised at the conference, but we present here only those recommendations that are very clearly and directly related to the goal of creating, integrating, and sustaining effective partnerships among patients, families, and communities and health professions education and healthcare organizations. Furthermore, we urge everyone, especially those in positions of responsibility, to take steps today to begin implementing these recommendations.

### Recommendation I

Make changes in the content and conduct of health professions education necessary to graduate practitioners who partner with patients, families, and communities.

To graduate healthcare providers who know how to partner with patients, families, and communities, we must change both *what* and *how* health professions students are taught.

Changes to curricular content and its delivery should take into account several principles, including the following:

- Exposure to new content should begin early and prepare learners for partnership

before they enter into experiential settings, such as clinical care settings.

- The concept of partnership should infuse didactic lectures, experiential offerings, and peer-to-peer learning.
- Content related to partnerships should extend beyond formal coursework and into standard clinical practices in both inpatient and outpatient settings.
- Patients and families must be welcomed as partners in all aspects and settings of the educational process, and they should be trained as co-educators of students.
- The experiential knowledge of patients and families should be used to enrich educational content.
- Content should take into account technologies patients and families can and do access on their own or that can be supplied to help them manage their health.

To implement this recommendation, we suggest the following actions:

**1. Develop a competency framework within health professions educational curricula focused on building effective partnerships with patients, families, and communities.**

These effective partnership competencies should be developed with input from all stakeholders (health professions educators, practitioners, and students as well as patients, families, and communities). A national group of relevant stakeholders should be convened for this purpose. They should build on existing health professional and interprofessional competency frameworks, and on existing tools and resources developed by patient

and family advocacy organizations, such as the Institute for Patient- and Family-Centered Care. Furthermore, to extend the work and its effectiveness over time, it will be essential to develop a cadre of health professions leaders who will champion partnerships among health professionals and patients, families, and communities. Thus, the content of curricula in health professions schools should emphasize leadership skills and embed partnership into leadership curricula.

**2. 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.**

Just as health professions students must learn about effective partnerships, so must patients, families, and community members. All stakeholders (health professions educators, practitioners, and students as well as patients, families, and communities) should come together and design a training program for patients who want to participate as partners in teaching health professions students in all settings where learning occurs. National organizations involved in patient advocacy would be logical conveners for this activity.

**3. Develop comprehensive faculty development programs focused on teaching health professions students how to build and sustain effective partnerships with patients, families, and communities.**

Faculty members should be held accountable for teaching health professions students about effective partnerships and for modeling what is being taught. For this to be possible, however, they must be supported by—and have the

opportunity to participate in—a robust and comprehensive faculty development program that has been jointly created by health professions educators, practitioners, and students as well as patients, families, and communities.

**4. Design and teach both coursework and experiential offerings in the institutions that educate health professionals to produce the effective partnership competencies mentioned above.**

This educational content should be based on currently existing examples of curricula related to building effective partnerships, and it should be taught together with patients, families, communities, and healthcare practitioners. Patients' involvement in educational activities can take many different forms. Some examples include sharing personal stories with students; role-playing interactions; consulting on curriculum development and review; co-authoring textbook chapters and journal articles; and mentoring students and/or hosting them for home visits.

**5. Convene a national group of stakeholders to develop measures—including structure, process, and outcomes measures—that institutions that educate health professionals can use to assess their performance in integrating partnership into their curricula.**

Institutions that educate health professionals must be held accountable for producing graduates who are competent at working collaboratively within and across disciplines and with patients, families, and communities to achieve better outcomes. Ensuring accountability will require a portfolio of structure, process, and outcomes measures of both patient and learner experiences.

**6. Develop a research and evaluation agenda for new educational programs that teach forming partnerships between health professionals and patients, families, and communities.**

Though some effective examples of programs aimed at forming partnerships exist, it is important to note that this approach is an emerging field. It will be necessary to link curriculum redesign and deployment efforts that teach partnership building with research and evaluation that identifies best practices in order to improve and facilitate the dissemination of these novel processes. Support for research and evaluation efforts should become a priority for funders such as the Patient-Centered Outcomes Research Institute (PCORI), grant-making foundations, and funders of health care.

**7. Work with accrediting agencies for health professions education institutions and health professions certification organizations (i.e., medical boards) to mandate curricular content and competencies for health professions students around effective partnering with patients, families, and communities.**

Organizations that accredit health professions education institutions can play a key role in fostering the development, spread, and improvement of competencies and curricula focused on building effective partnerships with patients, families, and communities. Implementing the foregoing sub-recommendations should provide accreditors the framework, faculty development curricula, measurements, and evidence base to play their role effectively.

## Recommendation II

Make changes in health professions education organizations and healthcare organizations necessary to facilitate durable partnerships, both new and existing, with patients, families, and communities.

In the United States, our system of health care is shifting toward greater emphasis on wellness and prevention, while also managing the chronic care needs and healthcare costs of our aging and increasingly diverse population. New organizational models, such as patient-centered medical homes and accountable care organizations, are creating new patterns of healthcare practice. These changes are translating into a greater recognition that health professionals, partnering with patients, families, and communities, need to work and learn about, from, and with each other. The success of these new models requires mutual respect, trust, new skills, and accountability among all involved.

Many have noted that health professions education has not kept pace with the rapid and fundamental changes in clinical practice and the new healthcare practice models. Nor have most health professions education organizations actively or meaningfully involved patients, families, or communities in the educational mission in ways that reflect their important role in health and health care.

Both health professions education and healthcare organizations have an important responsibility to inculcate new values and develop new skills among all involved: educators; health professionals; and patients, families, and communities themselves. This vision will require leadership and governance to create changes in both practice and education organizations and the alignment between them.

### 1. **Leaders of both healthcare and health professions education organizations must create new vision and mission statements and operational processes that meaningfully incorporate patients, families, and communities as partners.**

Leaders of healthcare and health professions education organizations should articulate a new vision for the future; communicate the imperative for re-aligning education with practice; and set expectations for new models that include patients, families, and communities as partners in governance, teaching, clinical care, and research. To accomplish these goals, organizational leadership in both healthcare and health professions education should undertake the following responsibilities:

- Model at every level of the organization the values and behaviors that welcome patients, families, and communities as partners.
- Create together with patients, families, and communities new mission, vision, and values statements that reflect partnership.
- Communicate values, set expectations, and establish incentives to partner with patients, families, and communities in substantive ways around the realignment of clinical practice and the education and training of health professionals.
- Formally assign responsibility for partnering with patients, families, and communities to a new or existing department, office, or position. The appropriate person(s) should be made responsible for ensuring that patients, families, and communities are meaningfully integrated in governance, teaching, clinical care, and research.

Ideally, passionate and objective leaders need to be assigned to facilitate this alignment and to be held accountable for outcomes. This also should be recognized as a legitimate area for scholarship and as a basis for academic promotion.

- Commit to enhancing organizational human resources capacity and functionality to support transformational changes in all settings. This includes integrating patients, families, and communities as partners in decisions, structures, and systems (such as hiring, rewards, continuing education, and accountability) related to all workers (staff, professionals, faculty, and administrators) in healthcare and health professions education organizations.

**2. The governance of organizations involved in the transformation of healthcare and health professions education—ranging from local health providers’ offices to large, multi-organizational systems, academic health centers, and schools for the education of health professionals—should be restructured to integrate the principles of partnership.**

A new system focused on co-created optimal health should strive for a goal of partnering with patients and families so that they may live well across all settings and through time. Governance for both healthcare and health professions education organizations needs to be better aligned and restructured to achieve this goal to maintain patients’ health, provide healthcare services, and educate healthcare professionals with the active involvement of patients, families, and communities. To restructure governance, healthcare and health professions education organizations should:

- Develop processes to select members of governing boards and oversight committees who represent the diversity of the community and who understand the shift toward partnership. Orient these individuals to the essential aspects of partnerships among patients, families, and communities and health professions education and healthcare organizations to enable them to be effective in organizational governance.
- Include community members in the ongoing monitoring and quality improvement processes of the organization’s performance and capabilities, and provide any additional resources needed to attain the goals above.
- Prepare leaders at all levels (boards of trustees, chief executive officers, vice presidents, deans, and faculty leaders) to lead their organizations in ways that are consistent with the new vision for health. They should learn about fundamental changes in health care, the current levers for healthcare change, the needed alignment between health professions education and healthcare organizations, and the need (and skills required) to partner with patients, families, and communities.
- Work with national organizations and accrediting bodies to promote leadership and governance around the concepts of alignment and partnership, and provide incentives to restructure in fundamental ways to incorporate patients, families, and communities.

**3. Leaders in healthcare and health professions education organizations should commit to preparing all team members (faculty, clinicians, direct health workers, students, and patients,**



## **families, and communities) to partner in co-creating educational curricula and optimal health care.**

Steps include:

- Build on existing competencies and professional requirements to ensure that learners at all levels are prepared to partner with patients, families, and communities. Set expectations for new knowledge, skills, and attitudes to facilitate cultural changes in higher education organizations that better reflect new expectations.
- Develop pilot projects, such as those described in the case studies<sup>2</sup> commissioned for the conference, to partner with patients, families, and communities, and create mechanisms to evaluate and disseminate innovative models that are successful.
- Prepare and support patients, families, and community members to serve on and lead key operational and oversight committees (quality improvement, patient safety, curriculum committees, etc.)

### **Recommendation III**

#### **Build the capacity for partnerships among patients, families, and communities and health professions education and healthcare organizations.**

A number of barriers prevent widespread, effective, and sustainable partnerships among patients, families, communities, health professions education, and clinical practice. These include society's assumptions about how health care works and the role of health

professionals; health professionals' assumptions that patients, families, and communities do not have the expertise to participate in the design and delivery of health care or health professions education; an imbalance of power in the patient-provider relationship that leads many patients and families to feel insecure and even fearful about expressing their views; a lack of receptivity to patient and family input among many health professionals and healthcare organizations; and the lack of structures and processes essential to supporting patient, family, and community partnerships.

Television, movies, and other media send powerful messages about health care and the relationships between patients and providers. For one generation, it was the fatherly *Marcus Welby*; for another it was the smart and impertinent young professionals in *House* and *ER*. Throughout, the messages often are of vulnerable patients seeking help from powerful figures who may demonstrate empathy and compassion, but rarely convey a message of equal partnership.

We are aware that a number of patient and family advocacy organizations and several national organizations, such as PCORI, the Institute of Medicine, and the National Institutes of Health's Clinical Translational Science Awards program, are developing resources to help healthcare organizations engage with patients, families, and communities. We believe these efforts likely will make important contributions to the field. The recommendations below should be informed by and coordinated with these efforts.

If we wish to move from a healthcare system based on "we are here to make you feel better" to a model of "we are partners, working together to create optimal health for you and for your community," we need new skills and supporting structures.

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<sup>2</sup> These case studies are included in the conference monograph that will be published in the coming months.

**1. Healthcare and health professions education organizations should establish values and behaviors that support patient, family, and community partnerships.**

Both healthcare and health professions education organizations are responsible for developing and implementing robust methods for receiving and responding to issues, concerns, and insights from patients, families, and communities in ways that ensure safety and freedom from repercussions. Patients, families, and communities have knowledge, experience, and ideas that organizations can use to provide better care and education. Patients, families, and community members will share these only if healthcare and health professions education organizations respond with receptivity and respect.

Organizational leaders are responsible for creating the infrastructure and mechanisms that promote authentic patient, family, and community partnership as a core value. They also are responsible for defining the relevant behaviors expected of professionals, staff, and learners. These include global behaviors expected of everyone and role-specific behaviors appropriate to particular circumstances. The end result will be most powerful if everyone (patients, families, community members as well as everyone who is caring, educating, learning, or otherwise working in the healthcare system) helps define partnership and the behaviors that support it.

Once these behaviors are identified, measurement and feedback (at the individual, unit, and organizational level) are needed to ensure accountability and sustainability. Ultimately, national-level measures will provide opportunities for cross-organizational learning and benchmarking. For instance, a patient might be asked to respond to a survey item

such as “During my visit, I felt welcomed as a full partner in efforts to improve care.”

**2. Define the skills needed by everyone involved in partnerships among patients, families, and communities and health professions education and healthcare organizations.**

Establishing and sustaining these partnerships requires skills that are new for many who are seeking or providing health care. A first step is for patients, families, community members, faculty, clinicians, staff, and learners to define together what skills are needed. Here, as a place to begin, are a few examples of such skills:

- Ability to build equal, respectful, and mutually beneficial relationships among all who are engaged in health care and health professions education;
- Ability to harvest and learn from the knowledge and experiences of patients and families through direct interactions, social media, and e-health;
- Ability to support change at both the individual and organizational levels; and
- Abilities in change management and continuous quality improvement.

A consortium of consumer groups and professional groups could work together to establish and promote these skills in a way that models the desired partnerships. This work could be hosted by consumer groups, “in their houses and according to their rules.”

**3. Create processes and an organizational structure that extend from local to national levels to advance patient, family, and community partnership in health care and health professions education.**

Although various types of patient and family partnerships, such as patient and family advisory councils, currently make important contributions to many healthcare organizations, their impact is felt primarily in individual settings or systems of care. For patients, families, and communities to have impact across the spectrum of health care and health professions education, their activities must be supported nationally as well as locally.

An over-arching organizational structure dedicated to advancing patient, family, and community partnership in health care and health professions education nationally as well as locally could help foster needed research and evaluation, disseminate best practices, and create networks that connect the people and organizations doing this work. The new structure must model the stated goals, such as visibly including patients as leaders. It also must have secure funding, established in a way that avoids conflicts of interest. One example would be a small tax on the Medicare Trust Fund, similar to the funding that supports PCORI.

The new organizational structure could:

- Develop and promulgate a national set of values and principles pertaining to partnership (these should build strategically on existing core principles).
- Develop and distribute education programs for the public, as well as curricula for multiple levels of learners (K–12, university, health professions, continuing professional development).
- Partner with social media, television, the film industry, and other communications-related organizations to create and promote educational messages consistent with the vision of

health and health care set forth in this report.

## Recommendation IV

**Make regulatory and payment reforms that require, support, and sustain partnerships among patients, families, and communities and health professions education and healthcare organizations.**

This is a time of great change in the way health care is organized, delivered, and paid for. Implementation of the Patient Protection and Affordable Care Act (ACA) has added momentum to the quest for new models of healthcare delivery and accountability that will enable us to simultaneously improve quality and lower cost. We expect these changes to help us achieve better health outcomes and improve the care experience for individuals and their families. Providers will be expected to be more accountable for their performance and use of resources; and individuals, families, and communities will bear more responsibility for their health and health care.

This climate of change and the innovations propelled by the ACA create unique opportunities for the changes in culture, attitudes, and practice that are necessary to achieving genuine partnerships with patients, families, and communities.

At a minimum, we believe the Centers for Medicare and Medicaid (CMS), and in particular, the Center for Medicare and Medicaid Innovation (CMMI), should embed partnership with patients, families, and communities into every new payment and delivery model they implement. Because CMS action so greatly influences payment and practice in the private sector, this commitment would have a force-multiplier effect that would help drive more rapid and widespread adoption of such partnership.

Hence, while payment and regulatory reform cannot serve as the sole stimulus for the transformation we seek, together with the other recommendations in this report, it can be an important catalyst, support, and means of accountability.

To implement this recommendation, we suggest the following actions:

**1. CMS and CMMI should take every opportunity, particularly those afforded by ACA implementation, to embed patient, family, and community partnership in new payment and delivery initiatives.**

Payment reform should be designed to create an understandable, coherent, mutually supportive framework of incentives and support that ensures sufficient financial motivation to care providers, patients, families, and communities. To do so, payments for partnership should be determined through robust accountability measures; coupled with sufficient support for training and technical assistance; and contextualized by transparency and feedback to ensure opportunities for continued improvement.

CMS/CMMI should specifically require partnership in the on-site governance, design, implementation, and evaluation of new payment and delivery models. The requirements should be robust enough to ensure that the criteria for partnership cannot be met simply through token representation on governing or operational bodies, or the creation of peripheral advisory groups that have little opportunity for genuine influence or decision making.

- Appropriate metrics should be used to assess the quality of the partnership process, as well as improvements in clinical quality and outcomes, and the

patient- and family-centeredness of care. Patient- and family-centered metrics should be used to both evaluate quality and calibrate payment for all new delivery and payment models. These metrics should include both patient-reported outcome measures (PROs) and measures of patient and family experience of care.

- CMS should allocate resources to more rapidly promulgate the development of PROs and advanced measures of patient- and family-centeredness and measures of patient and family experience of care that provide real-time feedback to clinicians.
- CMS/CMMI should provide adequate resources for training and technical assistance to ensure that patients, families, and communities can engage effectively in these partnerships. Adequate support and training should also be provided to ensure that clinicians, educators and administrators have the necessary skills for effective partnership.

**2. Requirements for partnership with patients, families, and communities should be integrated into the various types of ACA support for graduate medical education (GME) and workforce development.**

- Federal financial incentives for health professions education and training should be linked to demonstrated commitment to integration of partnership as described in the above sections of this report. Incentives should be linked to both front-end criteria that educational organizations must meet as well as accountability metrics that evidence an effective partnership process is in place.

- These requirements should be accompanied by federal support for training and technical assistance that ensures that patients, families, and communities as well as educators and learners have the necessary skills for effective partnership.

**3. Convene a summit of major education accreditors and professional certification bodies, with education leaders, clinicians, patients, families, and communities, to produce a framework and position statement that reflects a commitment and action plan for incorporating partnerships with patients, families, and communities into accreditation, certification, and maintenance of certification (MOC) standards across the professions.**

Large-scale transformation of education for healthcare professionals will not occur without the commitment of educational organizations and program leaders, who are heavily influenced by their respective accrediting bodies and the professional requirements for certification. Therefore accreditation and certification standards can catalyze the incorporation of partnerships with patients, families, and communities into both educational curricula and the clinical practice experience. Redesigned accreditation standards and certification competencies will speed dissemination of the structure and process elements needed to foster partnership in education and training processes. They will also encourage organizations to change more rapidly towards the professional culture, attitudes, and behaviors necessary for genuine partnership with patients, families, and communities.

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*The conclusions and recommendations from a Macy conference represent a consensus of the group and do not imply unanimity on every point. All conference members participated in the process, reviewed the final product, and provided input before publication. Participants are invited for their individual perspectives and broad experience and not to represent the views of any organization.*

*The Josiah Macy Jr. Foundation is dedicated to improving the health of the public by advancing the education and training of health professionals.*



## JOSIAH MACY JR. FOUNDATION

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