STRENGTHENING THE ROLE OF PATIENT & FAMILY LEADERS IN HEALTH CARE IMPROVEMENT

Strategic Opportunities for the Institute of Medicine

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Acknowledgements

This report seeks to channel the ideas of some individuals with invaluable perspectives on why patient and family advisors are critical to health and care and how to create structures for them to effectively contribute. They are listed in Appendix A. I am indebted to them for sharing their time and expertise and hope I have faithfully conveyed their insights. Diedtra Henderson made sure I had the essential background material—thank you D! Kate Burns and Sophia Yang were also helpful. Above all, I'm grateful to Dr. J. Michael McGinnis for offering me this opportunity to contribute to what I believe is one of the most significant efforts that IOM could undertake. His personal commitment is driving this project, and I am sure his well-honed skill at conceiving and delivering game-changing initiatives "with legs" for the long haul will carry the day. I hope this report helps.

Executive Summary

This report was prepared at the request of Dr. J. Michael McGinnis to assess its Patient and Family Council Leadership Network project (the Network), which is an initiative of IOM's Roundtable on Value and Science-Driven Health Care. IOM's goal is to help grow the leaders capacity as partners and contributors to the effectiveness of national, regional and local efforts for better care decisions, continuous care improvement, evidence development, better value, and better health for Americans. The report assesses activities to date and identifies compelling opportunities, activities and priorities for strengthening the Network and patient and family leadership in care improvement more broadly. The assessment included background research on patient and family advisory councils (PFACs) and IOM's work with others to advance these councils, and conversations with 16 contributors to the Network initiative.

In barely one year, IOM laid good foundations through communications, data gathering, resource development and convening. Key activities in 2014 included the creation of an online networking site; the development of a Patient & Family Leadership Resource Compendium that includes practical resources and summaries of existing research; a web-based national survey of PFACs; and second national meeting one year after the initial 2013 meeting. There is a sense that the network, though still very young, is beginning to jell. Staff are complemented for moving the work forward. Their inclusive and respectful manner is highly appreciated.

Suggestions for improving current activities focus on the online networking site on Yammer and, to a lesser extent the Resource Compendium. The themes in both areas are to clarify the need and collaborate with other organizations that are providing some similar services to avoid duplication and build on the respective strengths of each. In both instances it is likely that the newness of the Network, with many different interests coming

together for the first time, makes it difficult to narrow down the best approaches. Respectful inclusivity of multiple views is critical to build community, but complicates the task of focusing. With time and sensitive guidance, the Network can coalesce around priorities.

This work of coalescing is synergistic with the most compelling opportunities for growing and strengthening the Network. Since IOM views its role as an incubator, nurturing the Network toward a to-be-determined future, it will be critical to identify activities contributing most strongly to the Network's maturation, identify other resources that would help sustain it going forward, and articulate IOM's specific added value in the near and longer term.

Specific activities most likely to grow the Network and its influence fall into convening, communications, capacity building, and planning. New regional meetings, possibly hosted by other organizations and co-sponsored or promoted by IOM could strengthen personal connections. The regional meetings could feature training from experienced leaders, while the national meeting could devote more time to strategic issues. Educational webinars and informational conference calls for the field could significantly extend the Network's reach and help develop a shared view of issues, approaches, and priorities. Since the long-term growth and influence of the Network will require recognition of its value from influential stakeholders in health policy and practice, IOM could begin to convene providers, payers, accreditors, and medical educators, as well as congressional and executive branch leaders, to promote its vision and supportive actions in those areas. While the evidence base may not be sufficient to satisfy many of these stakeholders that action is justified, IOM would be sending an important directional signal to decision-makers who often must plan a year or more in advance for significant changes in policy or practice. Finally, helping Network leaders develop a strategic plan and prioritized action agenda can have the dual benefit of focusing the Network's efforts while building the experience of collaboration and consensus.

Proactive steps to engage leaders of other organizations to identify roles and responsibilities going forward will be fruitful if IOM helps guide the group toward the desired result of optimum synergy in the near and longer term. The discussions may stretch over several months and should ultimately inform and be informed by the parallel strategic planning work.

IOM's core mission has always been to provide evidence for decision makers in government and the private sector. It has a unique role in establishing the value and credibility of patient and family advisors in improving care and outcomes and potentially reducing costs. It is the natural leader of efforts to build the research agenda and the evidence base. Convening experts, including patient and family leaders, to identify needs and approaches could be a first step in 2015. Recognizing that the task will stretch over years, IOM could begin a calibrated approach to educating influential stakeholders about the "why and how" of strengthening patient and family leaders' input.

Introduction

Background and Approach to the Assignment

In the Fall of 2013, as part of its Roundtable on Value & Science-Driven Health Care, the Institute of Medicine (IOM) initiated activities to develop and incubate a virtual national network of hospital- and health center-based patient and family advisory council (PFAC) leaders. The project builds on pioneering Roundtable work since 2006 to improve health care and promote a learning health system that includes patients and families as active participants in all elements.[1]   In multiple venues and communications, IOM has advanced the principle that patients and families are critical to improving the quality of care delivered, better outcomes, and lower cost.   IOM's status under the National Academy of Science and its mission as adviser to the nation to improve health has both elevated and validated this principle in national discussions about health policy and practice.

IOM's Patient and Family Council Leadership Network project focuses on one concrete implementation channel: leaders of patient and family advisory councils (PFACs) that are created by hospitals and other health-centers as a means of getting input from the patients and families they serve. Through a wide variety of councils—some at the system or organization level, some at the individual unit level—patients and families can contribute to quality- and safety-improvement activities, building design, executive hiring, and patient communications, among other activities. PFACs began appearing in the late 1990s and have been promoted as resources in patient- and family-centered care for nearly 15 years.[2] They received a boost from the Affordable Care Act, which promotes patient and family engagement to improve the quality and safety of health care.[3]   Nevertheless, diffusion has been slow. As of 2014, only 41% of hospitals responding to a survey reported having created or expanded PFACs.[4]

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[1] See, for example, 13 IOM publications in the Learning Health System series since 2006. See also Patients Charting the Course: Citizen Engagement in the Learning Health System - Workshop Summary, October 2011, and Partnering with Patients to Drive Shared Decisions, Better Value, and Care Improvement - Workshop Proceedings, August 2013. See www.iom.edu/VSRT

[2] The Institute for Patient- and Family-Centered Care (IPFCC) appears to have published the first book in 2000: Developing and Sustaining a Patient and Family Advisory Council. Bethesda, MD. See http://www.ipfcc.org/resources/. Other complementary patient and family organizations are listed in Appendix B.

[3] See CMS' Partnership for Patients at http://partnershipforpatients.cms.gov/about-the-partnership/patient-and-family-engagement/the-patient-and-family-engagement.html

[4] Health Research & Educational Trust, American Hospital Association. Moore Foundation Survey on Patient and Family Engagement, 2014. Paper on results is in progress.

Against this backdrop, IOM's goal for the Patient & Family Council Leadership Network (the Network) is to help grow their capacity as partners and contributors to the effectiveness of national, regional and local efforts for better care decisions, continuous care improvement, evidence development, better value, and better health for Americans.[5] The desired capacity building is, in fact, bi-directional: to help leaders be more effective in their own institutions and beyond as a result of IOM's work, and to help them give IOM perspective on the most helpful ways to build a learning health system that is patient- and family-driven.

In the Fall of 2014, Dr. J. Michael McGinnis, IOM Senior Scholar and Executive Director of the Roundtable, commissioned Dr. Mary Jo Deering to do a strategic assessment of activities to date and opportunities for strengthening the Network and patient and family leadership in care improvement more broadly. Specifically, the assessment encompassed:
- Reviewing readily available background material on the state-of-play with respect to patient and family councils providing advisory input to health care delivery facilities;
- Reviewing activities of IOM, and in particular of the Roundtable, over the past year or two to work with others in helping to define, support, and advance synergy among the leaders of these councils;
- Conducting conversations with 16 contributors to IOM's Network initiative; and
- Providing a summary of observations on the IOM initiative's activities to date, including suggestions for compelling opportunities, activities and priorities going forward.

The 16 individuals were identified from a longer list provided by IOM that included funders and thought leaders as well as PFAC leaders. Ultimately, seven PFAC leaders, five thought leaders, and four funders were interviewed for approximately one hour each. The questions were developed by Dr. Deering and Dr. McGinnis. The individuals were asked about the clarity of IOM's intent, opportunities for synergy with other organizations, the value of current activities and how to improve them, opportunities for strengthening bi-directional communication, and the future state of the Network.

The insights from all these activities have been synthesized and presented thematically by areas where IOM could make significant contributions through current activities or expanded or new efforts. (See Perspectives section.)

Description of Recent IOM Activities on Care Improvement Roles for Patient and Family Leaders

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[5] IOM, Roundtable on Value and Science-Driven Health Care. Patient & Family Council Leadership Network: A joint project of the Roundtable's Innovation Collaboratives. Fact Sheet. July 15, 2014.

In just one year, IOM has laid the foundation for a vibrant and active network of patient and family leaders through a number of activities spanning communications, data gathering, resource development, and convening.

The new Network initiative was launched at a public meeting at the National Academy of Sciences on November 13, 2013.[6] The meeting's stated goals were:
1. Improve understanding of the national profile of hospital- and health-service based patient and family advisory councils.
2. Explore ways to improve communication and cooperation among advisory council leaders on their care system improvement activities and between those in the council leadership community and the leadership of national care improvement efforts.
3. Consider strategies for using information technology to increase communication with and among council leadership.
4. Discuss opportunities and priorities for collaborative action to build a strong networked capacity.

Sixty-one people attended the meeting in person; 59 people attended via Web-Ex. Nearly half of all the participants were current, former, or future volunteer patient/family advisory council members. The presentations highlighted some significant contributions to care improvement by existing councils. However, preliminary statistics on the number of hospital-based councils showed that there is a long way to go before councils are the norm. Discussions about communication opportunities revealed active networking is already happening through one nationwide listserv and other online networking models incorporating social media tools. Many ideas were shared about possible collaborative activities that would build on existing efforts. They included:
- Build the inventory and contact database of existing councils.
- Establish a means of regular communication.
- Develop an accessible description of the various models in play.
- Build the experience base of initiatives, successes, and false starts.
- Build the digital capacity for routine and immediate consultation among leaders on the front line.
- Undertake an effort to assess the business case for extensive patient and family engagement.
- Explore the indices that might be used to gauge the level of patient and family engagement in continuous improvement.
- Consider ways to expand involvement of the business community and the requirements for community needs assessment as resources for the work.
- Engage professional societies, such as those working in the IOM Best Practices Innovation Collaborative, in partnership initiatives.

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[6] Materials from the meeting may be found at
http://iom.edu/Activities/Quality/VSRT/2013-NOV-11.aspx

Building on suggestions from the November, 2013, meeting, IOM began to develop communications channels and evidence-gathering initiatives for the Network.   Early in 2014, a series of video clips was recorded, featuring experienced patient/family advisors and a senior official from the Patient-Centered Outcomes Research Institute (PCORI) describing concrete successes and opportunities through engaging personal stories. The videos were posted online through Facebook, YouTube, and a new private Network resource on Yammer.[7]

As a reflection of its bi-directional goal of engaging patients and families to help improve its own work as well as helping to improve theirs, IOM initiated a Patient and Family Council Leadership Network Consultative Group, a subset of patient and family representatives serving as volunteer advisors, together with representatives from organizations serving the field and from funding organizations as well as other thought leaders. The group meets by phone approximately once a month. It has provided input to the Network's 2014 activities: the Yammer site, a web-based national survey of PFACs, a Patient & Family Leadership Resource Compendium, and a follow up national meeting in November 2014.

The Yammer site was stimulated by a similar resource developed at Nemours as a "virtual advisory council" for patients and families. The IOM Patient & Family Council Leadership Network site now features an array of resources by topic, funding opportunities, speaker presentations, and discussion groups on diverse topics of interest to participants, among other components.

The online survey about the impact of PFACs encompasses demographics and content, organizational structure and function, improved patient outcomes, improved care and system processes, reduced personal and institutional cost, continuous learning and evidence generation, and statistical questions. The survey is being distributed through Network participants to their own channels. The survey is intended to expand findings from the survey completed by the Health Research & Education Trust mentioned above. Results are expected early in 2015.

IOM has been building a database of contact information for PFACs with input from its stakeholder organizations. The database will be significantly boosted by outreach to PFACs identified through CMS' Partnership for Prevention. The survey effort also has the added value of expanding the database and building up outreach channels.

With suggestions from its Consultative Group, IOM has nearly completed a first version of a Resource Compendium intended to help patient and family advisors in their own work and for wider dissemination by advisors and others. The compendium includes descriptions of PFACs, including general descriptions of their diverse roles and snapshots of successful PFACS; descriptions of published research on PFACs and related issues, including quality and safety improvement, patient- and family-relevant measures, patient engagement and

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[7] Yammer is software that allows an organization to set up a private social network on which diverse resources and communications can be posted and collaborative projects can be pursued.

empowerment, patient portals, C-suite engagement, frontline staff engagement, building design, value and efficiency, and learning from "real-world" examples; and other useful information such as patient and family resource organizations, e-Communication channels and forums, upcoming events, and a glossary. The Compendium is envisioned as a living document, to be regularly updated.

IOM has begun to communicate about its Network initiative to senior leaders from health policy and practice as part of its goal to advance knowledge of and support for PFACs among a wider circle of health leaders. It began by announcing its new initiative at the full Roundtable members' meeting on March 12, 2014. Roundtable members are leaders from core stakeholder communities (clinicians, patients, health care institutions, employers, manufacturers, insurers, health information technology, researchers, and policy makers). A panel of patient and family leaders led off the meeting, garnering praise from Atul Gawande for the "astounding ability [they bring] to quality improvement work." IOM speakers have presented on webinars of the Partnership for Patients (P4P), a public-private partnership working to improve the quality, safety, and affordability of health care. P4P was established by CMS as an outgrowth of the Affordable Care Act. It encompasses 3700 hospitals operating within 26 Hospital Engagement Networks, and its website lists 1,788 non-clinical organizations that have signed the P4P pledge .[8]

Perspectives on IOM's Role

The following sections integrate observations and suggestions from interviewees with perspectives that emerged from other components of the assessment work.

IOM and Facilitation of Communication Within the Patient and Family Leadership Community

IOM is building the base for a virtual network through several communication efforts. Its contact database and outreach channels are the critical enablers of a robust community. With the addition of PFAC contacts gathered through the survey and from the Partnership for Patients, the database will reach critical mass early in 2015 and enable widespread communications. Maintaining and growing the database will be important tasks going forward. IOM should also be mindful of opportunities to coordinate outreach with various stakeholders who have built up their own rich contact lists and channels over many years, to reduce duplication and optimize synergy.

Bringing the patient and family leadership community together, either in person or virtually, is highly appreciated. Everyone recognizes that in person gatherings are

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[8] See Partnership for Patients at http://partnershipforpatients.cms.gov/.

invaluable for building community, sharing, and learning. But they recognize that volunteers have time and resource challenges, especially in light of volunteers' often heavy medical responsibilities. One potential approach is to support regional meetings over the course of a year, hosted by one organization but co-sponsored by IOM and perhaps others too. A variation on this approach is to build on organizations' existing annual meetings, to make them an intrinsic part of the broader convening effort. Capacity-building should be an integral part of these meetings. In either case, having the IOM imprimatur on other organizations' meetings is valuable for strengthening their work and hence the field overall.

Webinars and conference calls also have an important role in convening. Webinars are widely most successful approach when an educational component (rather than dialog) is primary. Planning 6-10 informational and educational webinars over the course of a year could develop a curriculum of key topics, for example: the value of PFACs, getting started, recruiting, training, metrics, etc.. Stakeholder organizations specializing in one issue could lead a webinar; each webinar should spotlight successful PFAC programs. The archived webinars would be available for patient and family leaders to access on their own time, which is especially helpful for volunteers.   Some webinars might be extended to the wider public or target senior decision-makers.

Conference calls are perceived to work best for informational purposes (as opposed to education) or as working meetings. IOM's current conference calls with the Consultative Group are appreciated by the group's members as an opportunity to give input on IOM's plans.   As plans for the next 12-24 months develop, it's likely that more than one series of working conference calls will be needed to focus on specific activities; additional calls could be ad hoc or time limited. In addition, it would be valuable for IOM to host monthly conference calls open to the wider leadership community as a means of sharing progress and inviting input.

Recognizing the value of online networking, IOM initiated a Facebook page[9] early in 2014 as its public face and then began to develop the Yammer site as an invitation-only network. Maintaining a lively and valued online presence is time consuming, requiring frequent updates to convey a sense of substance and progress. The Facebook page does not appear to have been updated since March, as attention shifted to the Yammer site. While it is valuable in principle to have a public-facing online presence, the community may still be too young to show and grow a critical mass on Facebook. IOM should consider taking down the page until it is clear what its role will be, what resources will be available for it, and from whom.

The role and value of the Yammer site is not universally recognized, and its potential duplication with other efforts was raised by several people.[10] Some people suggested

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[9] See https://www.facebook.com/patientandfamilyleaders/.
[10] The IPFCC maintains a public Groupsite for its PFACNetwork that includes discussion forums, a shared calendar and more. See http://pfacnetwork.ipfcc.org/main/summary/. Other organizations listed in Appendix B also have valuable resources.

specific improvements such as adding blogging capability and chat rooms and bringing closure to discussion groups with summaries. People see value in having a single "go-to" site, which would not need to host all the content itself, but, in a hub-and-spokes model, would link out to other organizations' resources. This would have the added benefit of drawing attention to and validating these organizations' work. Attention to regional activity and resources would be helpful. It was not clear that this resource-sharing function would need to be private; it could be on a public website. The Yammer site may be encountering a problem shared by other private community approaches: their target audiences may be too busy to participate and may prefer simpler approaches like a listserv. Several people mentioned the IPFCC listserv as a useful "just in time" tool that lets users identify how frequently they want to receive updates. As IOM looks ahead to its 2015 agenda for the Network, it could be useful to canvass its current participants for their high priority communication needs and their preferred modalities. IOM could then work with other organizations to find complementary ways to fulfill those needs while striving to find the best single "doorway" to scattered resources. The Moore Foundation's site for its Roadmap for Patient & Family Engagement in Healthcare: Practice and Research has been cited as a model of effective communication to the field.[11]

All these activities raise the question: who are considered part of the "patient and family leadership community"? In addition to members of advisory councils, they may include patient and family leaders who serve only on specific advisory committees, such as for quality or safety improvement. IOM has included not only volunteers, but also paid staff (many of whom have been volunteers), leaders from patient and family centered organizations, and funders of patient and family leadership work. This breadth is a plus, enabling rich sharing and learning. Suggestions for enlarging the scope within the current hospital and health center focus include bringing in community health centers, public and rural hospitals, and ACOs, all of which should also have patient and family advisors, and a "passionate" nurse or physician to integrate the clinical voice. Current Network leaders could suggest additional names to bring into the conversation. Special efforts will be needed to promote the inclusion of more diverse patient and family representatives, including those in Medicare and Medicaid. The Network currently includes some members with experience in this area whose insights would be valuable. The Network should always maintain a strong connection to front line leaders.

It's also important to note that the field itself isn't sharply defined. Depending on the context, it seems to overlap with patient- and family-centered care or patient engagement; perhaps it's more accurate to say they all overlap. Indeed, many people felt that activities to strengthen advisory councils should be considered one part of a broader effort to elevate the role of patients and families across all aspects of health care. Moreover, considering the ultimate challenge of embedding support for patient and family leaders throughout the health sector, several people suggested that IOM consider including new stakeholders, who are influential in complementary areas, in its relevant activities. Examples given include the National Quality Forum, the American Public Health Association, the National Association of Community Health Centers, insurers, and accreditors. PICO, a national

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[11] The Roadmap site is at http://patientfamilyengagement.org/.

network of local faith-based organizations that work in health care and other issues, was suggested as a means of reaching disadvantaged populations who often constitute large proportions of hospital patients. As plans for the 12 – 24 month period get underway, these types of expansion could be considered for targeted activities.

IOM and the Evidence Base and Research Agenda on Results From Patient and Family Initiatives

IOM's official core function is to provide evidence for decision makers in government and the private sector. This is greatly appreciated by Network participants who were interviewed. They also recognized that since the field is young, the evidence base remains to be developed. Building the research agenda, promoting the research through public and private entities, and ultimately assembling the body of evidence into one of its authoritative reports for wide dissemination would be one of--if not the--most lasting contributions from IOM. In developing this work, IOM should consider the approach of the Patient-Centered Outcomes Research Institute, which emphasizes that patient and family input into decisions about both the subjects and the methods of research is essential.

This is not a short-term effort. The comprehensive, robust body of evidence required for an IOM consensus report will not be available for many years. But IOM can be influential in mapping out the trajectory and publicly committing to it. The initial step, convening experts, including patient and family leaders, to identify research needs and priorities based on promising opportunities for improving health and care, could take place in 2015. The scope would include evidence of the impact of patient and family advisors and other aspects of patient- and family engagement in improving the quality, safety, and efficiency of care; in reducing costs; and in improving outcomes, among other issues.

In addition, IOM can continue to use the Network itself to identify and publicize documented accomplishments of patient and family advisors on councils or committees. Showcasing best practices will advance both the spread and impact of these activities, strengthening the foundations of the evidence base. Concurrently, IOM can begin to develop consensus around meaningful measures of the impact of patient and family advisors. It could convene experts, with patient and family representatives, to identify "measures that matter" and methods for measurement.

The Resource Compendium, described above, can be a trigger for this wider effort. It includes peer-reviewed articles available to date, along with other useful information. There's a sense that this first version is a hybrid. The Compendium is currently targeted to patient and family leaders, for them to learn from and share with decisions makers to strengthen support for their work internally and in the community. However, several people observed that both patient and family leaders and senior decision makers would need a short version, with key points and examples. Planning for future versions could begin by asking a wide range of patient and family leaders what is needed. Planning could occur in the context of a strategy for building and communicating evidence from practice as

well as from research. The result might be two or more separate documents: One with a heavier emphasis on implementation for patient and family leaders; one focusing on research, including factors linked to successful start up, for decision makers; and possibly a third shorter document aimed at hospital and health center leadership with material on both the "why and how" packaged in a clear and effective manner.   Such a strategy would include roles for various stakeholders. For example, organizations that work in policy or research areas might have a lead role in developing the "why." Organizations that have developed expertise in training might have a lead role in compiling effective material on the "how." Cross-fertilization and participation by patients and family representatives in all components would be important.

IOM and Patient and Family Input Into Policy Initiatives

IOM is committed to learning from patient and family leaders to inform its work to build a learning health system that is patient- and family-driven. There are a variety of opportunities to do so through its myriad workshops and other meetings. IOM could use the Network as a "virtual" advisory council of its own, drawing on leaders with relevant contributions. Equally important, IOM can help channel the voice of patient and family leaders into other policy discussions.

Patient and family leaders recognize that, almost by definition, most volunteers have little if any experience in policy making. Their "credentials" come from their lived experience in the health care system, where all too often they have been *subjects of* care rather than *participants in* care. But it is precisely this expertise that is sorely missing from policy discussions about how patients and families can contribute to improved care and outcomes. There is clearly a language difference between their world and the policy world. This is all the more salient when the patients and family representatives whose voices are needed lack the economic or educational status to communicate in ways that professionals understand and vice versa.

Two strategies may help overcome the communication barriers. The first is to build the capacity of non-health professional patient and family leaders. Training can acquaint them with key policy issues, help them recognize areas where they can make the most important contributions, and coach them in how to make those contributions. Capacity building can also include finding opportunities for them to observe or listen in on policy discussions of interest to them. While IOM is not in the training business, it (with funders) could guide and support the Network and experienced training organizations to create policy curricula for patient and family leaders. The second strategy may be harder, but possibly more critical: health policy leadership should commit to "patient- and family-centered policy making"; they should examine the substance and process of policy making to identify specific ways to make them "patient and family friendly." Just as PCORI represents a new approach to defining and conducting health outcomes research, it seems plausible that thoughtful policy leaders could reshape their work so that the output had more traction in the world of patients and families, where (it is already acknowledged) "health happens."

IOM and the National Conversation on Patient and Family Advisory Council Strategies and Priorities

Patient and Family Advisory Councils are still quite new and far from fulfilling their potential across the nation. The fact that there are already organizations with significant track records working in the field is a reflection of the passion and dedication that are a hallmark of participants. Many people commented on the importance of building synergy through collaboration that uses the different strengths of organizations.   Some also felt that the time was ripe to bring greater focus to the Network. The two efforts can combine nicely. A collaborative approach could drive strategic planning to help the field coalesce around specific priorities and roles. With support from IOM, a small subset of Network participants from diverse organizations could develop an initial draft strategic plan and help lead the process of gathering input and promoting consensus. This activity could have dual benefits: not only could it produce a strategic plan and action items that could energize and focus stakeholders; the process itself could also be a model for how the plan could be implemented—i.e. participants would live the collaboration they want to develop.

Possible Priorities Moving Forward

IOM has characterized its effort as one of incubation. It would like to support the young Network and develop its capacity to provide value to patient and family leaders and to the wider health improvement effort. Challenges include finding activities most likely to contribute to the Network's maturation, identifying other resources that would help sustain it going forward, and articulating IOM's specific added value in the near and longer term. The following sections present targeted suggestions for addressing these challenges, drawing on insights mentioned above.

Areas of Particular Value Add

IOM's unique role in establishing the value and credibility of patient and family advisors in improving care and outcomes and potentially reducing costs is widely recognized. IOM's voice is like no other in the health care and health policy communities. It is a premier thought leader. Its endorsement of the work of patient and family advisors and of organizations that support and promote them is golden. Key activities that IOM excels at include building the research agenda and the evidence base and educating influential stakeholders about the "why and how" of strengthening patient and family leaders' input. In addition, by widely messaging its commitment to explore their value and to integrate them into its own work, IOM sends a strong directional signal that will point health policy and practice toward a patient- and family-driven learning health system.

Patient and Family Council Leadership Network Assembly and Maintenance

Face-to-face meetings, webinars, conference calls, and online communications are the connective tissue of a network.   Having two or more regional meetings in 2015 would benefit volunteers who may lack time and resources to attend a single annual national meeting. Several patient and family organizations already host meetings in different parts of the country, often with in-depth training. IOM could co-host or endorse these events and present an update on its Network activities and plans. IOM should quickly do a calendar call to leading stakeholder organizations to identify potential regional meetings. If IOM hosts a third national meeting in November, it might focus on strategic issues. It might invite policy makers to listen, learn and share. The timing would be favorable to a discussion of a strategic plan and action agenda, including roles and responsibilities of various stakeholders. (See Twelve- to Twenty Four-Month Agenda and Action Plan below.) In addition, IOM can help point people to the shared calendars of relevant events that several organizations have on their websites.

There is ample expertise in the Network to develop a series of 6 or more informational or educational webinars in 2015. A small educational steering committee could develop the curriculum, and Network participants could contribute ideas and content.   One session targeting senior decision-makers in health care might conclude the series late in the year. It could draw on senior hospital and health center leaders with successful patient and family advisory activities and include an IOM presentation on the evidence to date and its plans for the future.   In addition, IOM could host a monthly conference call open to the entire Network to provide updates on activities.

IOM should verify that the Network's online community activities are fulfilling their intended need. Asking participants what they want and how they want it would be a first step. Doing an environmental scan of other activities that can fulfill these needs and working with stakeholder organizations that already support them would help identify the most useful roles for them and IOM.   In the interim, IOM should either take down the Facebook page or keep it well populated and attractive and promote it widely.

Resource/Research Compendium

IOM should consider the role of the Resource Compendium within two contexts: as a tool for patient and family leaders (its current focus) and (as a different, possibly separate document) as part of a broader strategy to identify the research agenda and promote development of the evidence base. The first version of the Compendium straddles the two areas by offering both useful resources and summaries of existing research on impact. This version can make a contribution whether or not it delivers exactly the right content in the right way. In other words, the perfect should not be the enemy of the good in jumpstarting this work. Having an Executive Summary would help. Future work should clarify the intended audience. A second edition of the *Resource* Compendium that also targeted patient and family leaders could be conceived as a more explicit implementation tool, and possibly be led by organizations specializing in this work. A *Research* Compendium that focused on summarizing research to date could be a first start at evidence communication to decision-

makers, acknowledging that the evidence is insufficient to authoritatively establish impact. Disseminating this Compendium with a clear framing message, including longer-term intentions, would be a good first step. Initiating work to identify "measures that matter" would be a helpful second step. A third, shorter document with key messages on the value of PFACS and how to successfully set them up, could be valuable in helping hospital and health center leaders take action.

Synergy Among Leaders

There is a wealth of talent and resources in this relatively young community, reflecting the deep passion and dedication that drives it. Pioneers in the field have built impressive work in advocacy, education, training and other support for patient and family advisors. There is strong support for collaboration. IOM could convene organization leaders in the first quarter of 2015, starting with those listed in Appendix B but including others that offer critical strengths. The task of identifying roles and responsibilities will take many discussions over months. A thoughtful process that rigorously hews to the path of achieving optimum synergy can succeed. IOM's special contribution includes guiding the process and emphasizing the desired result.

Leader Interface with the Policy Agenda

There are opportunities to strengthen leaders' input to policy at two levels. Leaders working on the front line of PFACs and committees have invaluable insights into needed change but often lack the skills and channels to effectively deliver them to policy makers. IOM could promote policy capacity building by organizations that already offer training and education for leaders and provide content to help build curricula. It could include policy updates in the monthly calls suggested above. There are also leaders who already have the experience to be effective participants in policy discussions. IOM can identify individuals with specific or general expertise, include them in all relevant meetings of its own, and promote their inclusion into policy discussions led by other organizations, including the Federal government. The latter steps can help develop "patient-centered policy making" processes and policies that strengthen patient and family contributions.

Strategic Convening

To infuse support for patient and family advisors across the health care sector, IOM will need to reach senior people from diverse areas, including providers, payors, accreditors, research and funding, and medical education; officials from the legislative and executives branches are also critical audiences. The evidence base will not be solid enough by the end of 2015 to satisfy many of these stakeholders that quick action is justified. However, it would be very helpful to convene them individually or jointly during the year to share IOM's perspective and plans. The sessions should include presentations by their peers who are already professionally persuaded of the opportunities and by "C-suite" medical officials who have documented success in their organizations. This would send an early directional

signal to decision-makers, who often must plan a year or more in advance for significant changes in policy or practice.

IOM could also start the convening process for evidence development by initiating meetings of experts to identify research needs and strategies, including meaningful metrics. Modeling PCORI's approach, patient and family leaders should be involved in identifying both the scope and potential methods for the research.

Twelve- to Twenty Four-Month Agenda and Action Plan

Many of the suggestions above are entirely in the purview of IOM. It can decide which of the potential priorities to pursue for its broader national agenda, benefitting from contributions from Network participants.

In addition, having a clear plan for moving forward that is owned by the Network can help Network participants coalesce around priority activities. A 12 – 24 month strategic plan should assume that the long-term trajectory will be marked by the maturation of the Network and a to-be-determined, post-incubation future. All components of the plan should work toward those ends.   IOM could convene a strategic planning steering committee in early 2015 to develop drafts and help guide the process of gathering input and building consensus. The draft of the plan could include any of the priority activities listed above that garner quick support from the steering committee and reflect those that IOM may have decided to pursue as part of its own role. The plan should be informed by the results of the discussions on synergy mentioned above. Having a limited number of critical items for Network as a group to pursue—no more than four annually—will be most effective in focusing efforts.

Conclusions

Looking at all IOM's written material and comments made in meetings over the past year, it seems that IOM's stated vision and intent are in line with the needs perceived by interviewees. Some implementation activities whose underlying rationale is sound may not be contributing as effectively as planned, namely the Compendium and the Yammer site. This seems partly to be a reflection of IOM staff's much appreciated efforts to be respectful and inclusive of all input. When the field is so young and interests vary widely, it is difficult to identify the highest value approaches.

The path forward will be marked by two fundamental assumptions: collaboration is key to building the Network from within, and IOM's unique status should be leveraged to change the landscape in which the Network will work to increase its impact.

Appendices

Appendix A: Individuals Interviewed

David Andrews, Patient Advisor, Georgia Regents Medical Center

Chrissie Blackburn, Principal Advisor, Patient and Family Engagement, University Hospitals Case Medical Center

Kim Blanton, Patient Advisor, Vidant Health Center

James Burrows, Director, Service Excellence, Nemours

Crispin Delgado, Program Officer, Patient Engagement, Blue Shield of California Foundation

Hala Durrah, Chair, Women and Children's PFAC, Anne Arundel Medical Center

Dominick Frosch, Fellow, Patient Care Program, Gordon & Betty Moore Foundation

Libby Hoy, Family Advocate and Founder, Patient & Family-Centered Care Partners

Bev Johnson, President and CEO, Institute for Patient- and Family-Centered Care

Maulik Joshi, Senior Vice President, Research, American Hospital Association/Health Research & Educational Trust

Barbara Lewis, Co-Chair, Global PFAC, The Beryl Institute; and member, Kaiser Permanente Regional PFAC

Susan Mende, The Robert Wood Johnson Foundation

Juliette Schlucter, NYU Langone Medical Center

Sue Sheridan, Director, Patient Engagement, Patient Centered Outcomes Research Institute

Dennis Wagner, Partnership for Patients, Center for Medicare & Medicaid   Innovation, CMS

Appendix B: Complementary Patient and Family Stakeholder Organizations[12]

Patient and Family Advocacy and Support Organizations

The Beryl Institute
Texas Office:
3600 Harwood Rd, Suite A
Bedford, TX 76021
Washington Office:
611 Pennsylvania Ave, SE , Suite 424
Washington, DC 20003
Toll Free 866-465-5824
www.theberylinstitute.org

Institute for Patient- and Family-Centered Care
6917 Arlington Road, Suite 309
Bethesda, Maryland 20814
301-652-0281
www.ipfcc.org

Institute for Healthcare Improvement
20 University Road, 7th Floor
Cambridge, MA 02138 USA
Toll-Free: 866- 787-0831
www.ihi.org

Patient Family Centered Care Partners
5199 Pacific Coast Highway, suite 306
Long Beach, CA 90804
562-961-1100
pfccpartners.com

Research and Grant Organizations

Agency for Healthcare Research and Quality (AHRQ)
Office of Communications and Knowledge Transfer
Gaither Road, Suite 2000
Rockville, MD 20850
301-427-1104
www.ahrq.gov

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[12] This is not intended to be a definitive list. It includes organizations most frequently mentioned by people during conversations.

Blue Shield of California Foundation
50 Beale Street, 14th Fl
San Francisco, CA 94105-1819
415-229-6080
www.blueshieldcafoundation.org

Gordon and Betty Moore Foundation
1661 Page Mill Road
Palo Alto, CA 94304
 650-213-3000
www.moore.org

Health Research and Educational Trust
(in partnership with the American Hospital Association)
Chicago Office:
155 North Wacker, Suite 400
Chicago, IL 60606
312-422-2600
Washington Office:
800 10th Street, N.W. ,Two CityCenter, Suite 400
Washington, DC 20001-4956
(202)638-1100
www.hret.org

Patient-Centered Outcomes Research Institute
1828 L St., NW, Suite 900
Washington, DC 20036
202-827-7700
www.PCORI.org

Robert Wood Johnson Foundation
Route 1 and College Road East
P.O. Box 2316
Princeton, NJ 08543-2316
877-843-RWJF (7953)
www.rwjf.org