An Introduction to the Patient Experience Policy Forum
AN INVITATION

In sharing the attached document, we introduce the Patient Experience Policy Forum (PXPF), our focus and the issues we care about. PXPF is not a special interest, rather we act in the human interest. We look forward to engaging further with you.

PXPF is a unique advocacy organization that brings together seasoned patient advocates and healthcare leaders from across the country who are committed to working side by side to impact policy and improve the experience for both those served by and those who work in healthcare every day. We have used this “two-by-two” model from our beginning to identify priorities, develop policy statements and objectives and meet with and engage decision makers.

Our intent in sharing this information with you is to do the following:

- Identify and elevate issues that are important to both patients and healthcare organizations
- Contribute the unique and aligned perspective of patients and healthcare leaders to these issues of importance
- Advocate for changes in policy that specifically impact the experience of patients and families and the healthcare workforce
- Present ourselves as a resource to help advance policies that will improve healthcare for all

Key questions we believe are essential to consider in developing any health-related policy include:

- Have we considered the impact of this policy on patients, care partners and healthcare leaders?
- Have we included the voices and lived experiences of patients, care partners and families in our discussions?
- Have we identified how success will be measured and whether these measures reflect the needs of patients, care partners and healthcare leaders?
- Have we developed this policy with an acknowledgement of and commitment to dismantle existing health disparities and ensure equitable outcomes?

PXPF is actively engaged in transforming healthcare and seek to collaborate and engage with your organization in crafting policy where our goals and interests align. We look to add our unique voice to advance the issues and policy ideas core to our purpose and reflected in the pages that follow.

Respectfully,

Shari Berman  
Co-Chair, PXPF  
sharibermandicker@gmail.com

Rick Evans  
Co-Chair, PXPF  
rie9003@nyp.org

Jason A. Wolf  
President & CEO, The Beryl Institute  
jason.wolf@theberylinstitute.org
EXECUTIVE OVERVIEW

PURPOSE & IDENTITY
The Patient Experience Policy Forum (PXPF), supported by The Beryl Institute, is a broad-based and diverse coalition of patients, family members, caregivers, and health care professionals uniquely led by a balanced board of patient/family partners and senior patient experience leaders. Our purpose and commitment is to advocate for and help shape policy at the national and local levels on issues that directly affect patient and family experience and elevate the human experience in health care. PXPF operates:
- With a unique 2-by-2 model which balances the voices of patients, family members and care partners with those who lead in healthcare organizations.
- Free from influence of those with any financial or commercial interest in our outcomes and actions. We are not a special interest; we work for human interest.

OUR COMMITMENT
We believe that the interests of patients, families and caregivers must drive all public policy aimed at improving the health care experience. We advocate for policies that will:
- **Advance Patient-Provider Partnerships:** Patients and families and their clinical care providers must be at the table at all levels of health care policy-making.
- **Strengthen Support for Patient and Family Involvement:** Patients and families must be provided with education, tools and support to effectively participate in policy-making and in their own care.
- **Strengthen Support for Professional Involvement:** Health care professionals must be provided with education, tools and support to build effective relationships with patients and families.
- **Reduce Disparities:** Disparities in the care experienced by patients and families from vulnerable and marginalized populations must be reduced or eliminated entirely.
- **Improve Patient-Centered Measurement and Reporting:** Methods of assessing and reporting patient experience must be made more efficient and effective for both patients and providers.
- **Elevate the Value Case:** The direct connection of patient experience to health care outcomes must be clearly defined and integrated into all relevant policy and reimbursement structures.

OUR CURRENT FOCUS
Our current priorities are focused on two points from our commitments above:
- Strengthen Support for Patient and Family Involvement
- Improve Patient-Centered Measurement and Reporting
We are also expanding our efforts in 2021 to address our critical commitment to Reduce Disparities.

ACTIONS TAKEN
The documents that follow reflect our current policy statements and include:
- **Patient and family recommendations for addressing visitation policies during COVID-19.** A policy statement offering clear actions healthcare organizations can take to address visitation at this time. [Read]
- **We must partner with patients as we redefine healthcare in the post-COVID-19 era.** A statement, published in Becker’s Hospital Review, on the critical need for partnership with patients and families. [Read]
- **Next Steps For Modernizing And Democratizing National Patient Surveys.** A Health Affairs Blog published with specific steps on how experience measurement and our incentive systems must be reimagined for the future. [Read]
- **Let patients speak for themselves on the Biden task force and elsewhere.** A STAT First Opinion piece calling for patient and family presence in policy making overall. [Read]
- **An Action Plan for The New Existence in Healthcare.** A call to action developed through the voices of The Beryl Institute community on what actions we will be called to take in moving healthcare forward.
APPENDIX – TABLE OF CONTENTS

The appendix contains the following documents:

<table>
<thead>
<tr>
<th>Article/Resource</th>
<th>Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient and family recommendations for addressing visitation policies during COVID-19.</strong> A policy statement offering clear actions healthcare organizations can take to address visitation at this time.</td>
<td>4 - 7</td>
</tr>
<tr>
<td><strong>We must partner with patients as we redefine healthcare in the post-COVID-19 era.</strong> A statement, published in Becker’s Hospital Review, on the critical need for partnership with patients and families.</td>
<td>8 - 11</td>
</tr>
<tr>
<td><strong>Next Steps For Modernizing And Democratizing National Patient Surveys.</strong> A Health Affairs Blog published with specific steps on how experience measurement and our incentive systems must be reimagined for the future.</td>
<td>12 - 17</td>
</tr>
<tr>
<td><strong>Let patients speak for themselves on the Biden task force and elsewhere.</strong> A STAT First Opinion piece calling for patient and family presence in policy making overall.</td>
<td>18 - 21</td>
</tr>
<tr>
<td><strong>An Action Plan for The New Existence in Healthcare.</strong> A call to action developed through the voices of The Beryl Institute community on what actions we will be called to take in moving healthcare forward.</td>
<td>22 - 23</td>
</tr>
</tbody>
</table>
Patient and family recommendations for addressing visitation policies during COVID-19

Geri Lynn Baublatt, MA – Patient Family Advisor, PXPF Patient Family Partnership Subgroup
Chrissie Blackburn, MHA – PXPF Board member, Patient Family Partnership Subgroup Co-Chair
Nikki (Charisse) Montgomery, MA, M.Ed, GPAC – PXPF Program coordinator
Courtney Nataraj – PXPF Board member, Patient Family Partnership Subgroup Co-Chair

The COVID-19 crisis has called on healthcare organizations globally to take measures to provide for the safety and well-being of both those served and those who work in healthcare every day. In the immediate days after the surge in this crisis, hospitals and healthcare organizations had to make difficult choices that continue to have a lasting impact on the opportunity for family presence and the involvement of care partners in care settings for both COVID and non-COVID patients. While actions have varied across organizations, and virtual opportunities sprang into existence in many places, the impact of decisions around visitation and the presence of that support must be revisited and understood.

Policies developed by state departments and boards of health are used by hospital leaders to develop visitation guidelines that protect public safety and the safety of healthcare workers. In the healthcare system – which includes hospitals, ambulatory facilities and clinics – visitation policies have varied from state to state, and the restrictions set by state departments of health have even led some hospitals to suspend visitation for some patients or for specific durations of time.

It is essential to acknowledge and act on the need for policies and practices that ensure this basic need for care partners is met and the associated evidence-based outcomes that result from effective patient and family engagement are realized. To address this moment of challenge, and the decisions related to visitation, we offer the following recommendations:

1. **When looking at visitation policies, care partners must be seen as active and essential members of the care team** with steady presence in the patient’s care (even before the pandemic), and visitors are people who are not actively part of the patient’s care or care team.

2. **Hospital visitation policies must include the voices of patients and care partners**, as well as the real and practical concerns of healthcare leaders and workers. Importantly, these visitation policies must be based on the latest scientific evidence rather than political pressures.

3. **As policies are developed, it is essential for departments of health to consider the safety impact of care partners** in defining how hospitals regulate the number of visitors, the processes for COVID-19 versus non-COVID patients, and how patient and care partner safety are managed.

4. **Patients, care partners, healthcare staff and the community must have a clear understanding of visitation policies**, and policies must be flexible enough to accommodate individual family circumstances and risk factors. It is essential that visitation policies be updated regularly on healthcare system websites and publicized through social media and other communication.
platforms, so patients and visitors have a clear understanding of the guidelines and whom to contact with their questions and concerns.

5. **It is essential that all people in the healthcare setting wear masks, including visitors, staff and care partners.** Mask wearing is considered a necessary step in COVID-19 infection control and must be required in all healthcare settings. Hospitals must provide masks for all patients, care partners and visitors who do not have one.

6. **All patients must have the option to have a care partner present in the healthcare setting.** Care partners are currently considered imperative for pediatric patients, medically complex patients and patients with dementia, post-op delirium, developmental delays and disabilities, regardless of age. The importance of care partners, however, extends beyond these populations. Research shows that family presence and participation contribute to a loved one’s quality of care and quality of life. Care partners often serve as advocates and protect the safety and wellbeing of patients, in addition to managing consents for care. The presence of care partners in the healthcare setting should be seen as a benefit to safety, not just as a risk. However, keeping care partners safe involves some specific policy imperatives that can slow the spread of disease while protecting patients’ and care partners’ ability to advocate and participate in their care. The following scenario provides one example:

   *When my mom needed to visit the hospital because of an issue with her pacemaker, I checked the hospital’s website, which said that for seniors without COVID-19, one family member was allowed to come in as their care partner / family caregiver. But when I called to ask questions about PPE, I was told the policies about care partners changed daily, and the website wasn’t up to date. At that time, they only allowed a care partner in one time and for just one hour — and only if it was an end-of-life situation. Serious cardiac surgery on an 87-year-old can quickly turn into an end-of-life situation. But even if I went, how would I know which one hour to choose if I was allowed in? Who should I talk with to negotiate this? In the end, I was told I couldn’t come into the hospital at all. Since I couldn’t be present, I asked for a call when the physicians rounded, but they couldn’t tell us when the doctors would round, and the physicians wouldn’t proactively call me or my sister-in-law, who is the medical Power of Attorney. Luckily, my mom was lucid and able to call us on speaker. The audio wasn’t great, but our conversation revealed a medication issue that could have been life-threatening. The doctor said it was very important we’d been on the phone to tell him this. Yet, this was all dependent on my mom being able to make the call.*

This powerful patient story illustrates the importance of care partners, the threats to patient safety when care partners cannot be engaged effectively and the necessity for supporting their engagement with policies and resources.

7. **There should be no more than two identified care partners allowed for any patient during the duration of a hospitalization.** Healthcare settings have been challenged with limiting the number of care partners and screening those care partners regularly so ensuring manageable and consistent numbers enables effective contact tracing in the event of COVID-19 exposure.

8. **Care partners’ temperatures and symptoms must be checked upon entry.**

www.pxpolicyforum.org
9. When in-person visits are not possible for care partners due to public health concerns or family participation factors, **all efforts must be made by healthcare staff to facilitate quality virtual visitation.**

10. Overnight stays are an expected mainstay in hospital pediatric care; similarly, **special accommodations for overnight visits must be made** for all based on patients’ needs and ability to participate in care.

11. In order to ensure the safety of visitors in COVID-19 patient areas, **hospitals must provide/supply appropriate personal protective equipment (PPE) for visitors.** This PPE must consist of masks, shields, gowns and gloves. End of life visitation and visitation related to other extenuating circumstances must be considered on an individual basis.

12. **Data on the various special circumstances for visitation must be captured, examined and monitored for disparities** based on socioeconomic status, race and ethnicity, disability, and other factors. Special considerations for childcare and complex social situations must also be managed in ways that produce equitable outcomes. When disparities are identified, policies must be revised to establish equity.

While many suggestions and strategies for visitation have emerged during this time, this set of recommendations is intended to provide both broad perspective and specific guidance from the voices of patients and families in partnership with innovative healthcare leaders. And while not every organization may be able to address each item, a consideration of this wider view is critical in understanding the comprehensive nature of the visitation opportunity during this crisis. In addressing this and other efforts with this complementary and integrated perspective, the PX Policy Forum believes actions can and must be taken to address this issue that is so central to healthcare and so critical for those healthcare serves every day.

**References**


About Patient Experience Policy Forum

The Patient Experience Policy Forum (PXPF), supported by The Beryl Institute, is a broad-based and diverse coalition of patients, family members, caregivers and healthcare professionals uniquely led by a balanced board of Patient/Family Partners and senior patient experience leaders. Our purpose and commitment is to advocate for and help shape policy at the national and local levels on issues that directly affect patient and family experience and elevate the human experience in healthcare. We do so through convening policy forums, educating policy makers, sponsoring advocacy events, providing communication updates and publishing calls to action.

About The Beryl Institute

The Beryl Institute is the global community of practice committed to elevating the human experience in healthcare. We believe human experience is grounded in experiences of patients & families, those who work in healthcare and the communities they serve. (https://www.theberylinstitute.org/)
We must partner with patients as we redefine healthcare in the post-COVID-19 era

Shari Berman – Co-Chair, Patient Experience Policy Forum; Courtney Nataraj, Patient Adviser and Board Member, Patient Experience Policy Forum; Charisse Montgomery – Program Coordinator, Patient Experience Policy Forum - Tuesday, June 16th, 2020

Over the last few months, millions of people have been asked to practice physical distancing to prevent complications and deaths from COVID-19. Some of us are at greater risk than others in this pandemic. Iver Nataraj, a 9-year-old boy with chronic lung disease, born a micro preemie, is one such example. Iver,
who is immunocompromised, is especially at risk during these times. COVID-19 presents a new set of challenges for Iver’s family because exposure to the coronavirus could be deadly for him.

Iver’s mother, Courtney Nataraj, is a patient/family adviser at NewYork-Presbyterian Hospital. Ms. Nataraj, experiencing fear, isolation and worry in light of COVID-19, was surprised when Iver described feeling peaceful and loved in quarantine, despite the difficulty of isolation. He described feeling happy to wear his protective mask because he felt protected.

As states start to open back up and life resumes, the risk has not gone away. Most people have not seen a doctor for regular visits, and it begs the question: What will it take for us to feel as peaceful, safe and protected as Iver feels in this new reality?

This new COVID-19 environment will be with us for the foreseeable future, and we must think about what measures need to be put in place to ensure patients of all ages feel safe to return to healthcare — for them to trust the system. Patients need us to paint a clear picture of what using healthcare will be like in this new reality, and they need to know what healthcare providers are doing to keep patients and their families safe.

In doing so, it is important to take a fresh look at what matters most to those receiving care and how it will change the patient experience in healthcare. Patients are still getting sick, but they are not going to the hospital as they would have even a short time ago, because they are afraid of coming into contact with COVID-19 at the hospital or in the clinical setting. Patients with chronic or new issues are staying at home, and many tests and procedures have been put on hold. Many patients and caregivers managing chronic conditions don't know if the risk of seeking care outweighs the benefits.

"I was scheduled for a cardiac test, to follow up from my cancer treatment years ago," said Shari Berman, co-chair of The Beryl Institute's Patient Experience Policy Forum (PXPF). "It has been put on hold, and I am not sure when I will feel safe to return to have the test done."

As we consider a future when COVID-19 is still present, but hopefully less of a crisis, the emotional and mental health of patients will need to be addressed. How will we help families feel safe in a waiting room and confident enough to go in for a procedure or to visit an emergency department?

Healthcare organizations are working through these issues. Hospitals that have treated COVID-19 patients are figuring out how to segregate treatment areas as much as possible. Use of public areas, such as waiting rooms and elevators, is being totally rethought. Entire scheduling systems will need to be overhauled to allow for social distancing. Telemedicine is here to stay, and patient expectations have changed with it.

"It's a whole new world," said Rick Evans, chief experience officer at NewYork-Presbyterian Hospital and co-chair of PXPF. "We will be in this situation for a while, and we want our patients and our staff to feel and be safe."

Talking to patients and partnering with them as hospitals and clinics develop new systems and protocols is essential. Oftentimes, hospital administrators think they know what patients want, but hearing from patients and knowing what matters most to them is critical when determining how to proceed. In this crisis, it is more important than ever to ask patients what it would take to make them feel safe.

"I would like to be contacted by my son's doctor, who can walk me through the best way to treat Iver. If I need to bring him in for an appointment, I want him to tell me how safe he feels it is to do so," said Ms. Nataraj. "I also think it would be helpful to connect patients with a peer-to-peer program where they can talk to others who may have the same concerns."

Because many hospitals have had to restrict visitors, patients and their families are experiencing hospitals and clinics in a totally new way, alone and sometimes confused. The support structure they depend on is
absent. With these restrictions likely to continue, the role of the patient and family adviser (PFA) can help guide health system leaders through unchartered territory together, staying focused on a commitment to caring for patients and families with compassion, especially in this uncertain and frightening environment. Some health system leaders have eagerly partnered with PFAs to create innovative solutions to new problems.

“Our patient partners have been essential as we develop new communication tools and are compelled to share difficult messages with our patients and our community. Their insights and feedback, as always, have helped steer us in a different direction than where we were headed many times,” said Sheila Moroney, patient experience officer at Minneapolis-based Hennepin Healthcare.

At Cleveland-based University Hospitals, Chrissie Blackburn, principal for patient and family engagement, describes how her organization has been utilizing patient and family partners during COVID-19. "We partnered directly with our patient family partners to add patient- and family-centered language to our visitation restrictions. We also developed a 'Be Prepared' document to help people start thinking about what they would want should they became seriously ill. Additionally, a 'Get to Know Me' poster was developed by the group, which could be filled out electronically by families and hung in patient rooms. Working with our patient and family partners is a key component to much of what we do at University Hospitals."

Diversity and equity should also be considered as healthcare leaders work to eliminate disparities in care and outcomes and build trust with underserved communities. Initial data from the COVID-19 pandemic already point to alarming disparities in treatment, impact and outcomes. Ensuring that we reach all patients, especially those who are typically underrepresented, is critical. In addition to PFAs, some hospitals use focus groups, and all use surveys to collect information on patient experiences, perspectives and preferences. Going out into the community and meeting patients where they are, even virtually, is a way to ensure that all voices are heard. It is also important that we communicate effectively with patients, using words and explanations they understand on patient portals and in other venues, including social media.

Until a vaccine is widely available, patients and their families will experience fear or anxiety in their healthcare encounters, but patients are also experts in their care and can teach healthcare administrators, staff and clinicians to be more responsive to their needs. Learning from their lived experiences about protecting and caring for themselves and their loved ones will help prepare healthcare systems for responsive, equitable and safe care, during and after COVID-19.

The landscape has changed beneath our feet, and everyone is struggling to find the safest, most compassionate and effective way forward. We believe the answer lies in working together: patients and community members, hospital leaders, infection control experts, physicians and others, talking together and figuring out how to stay safe, while ensuring people get the healthcare they need. PXPF, which has always been a collaboration between patients, families and healthcare leaders, believes this paradigm is more relevant than ever to help hospitals and healthcare organizations address the COVID-19 crisis.

Essential to patient safety and confidence is the need to:

- Maintain a safe environment.
- Test and screen patients and staff for COVID-19.
- Use telemedicine and virtual means to both provide treatment and communicate with patients and families.
- Develop more family-friendly visitation policies in the new COVID reality.
- Communicate frequently and transparently with patients and families to create a shared understanding of how they can maintain their own safety at home, in their communities and during healthcare visits.
PXPF advocates for policy change to improve the patient experience during and beyond this pandemic. In this environment, we advocate:

1. For hospitals and clinics to involve patients and families in the reopening process proactively and extensively. Deliberate efforts must be made to establish dialogue and plan for the future together.
2. For government and industry leaders to expand patient access to telemedicine services and to ensure they are covered by Medicare, Medicaid and private insurance. Universal availability of broadband in all communities should also be prioritized to support the above.
3. For the entire healthcare and research community to use data to study and address inequities and disparities that have become more apparent during the COVID-19 crisis.

Our collective hope is that health system leaders and patient and family leaders find ways to instill trust and make sure all people, from all backgrounds, feel safe and protected in this new environment, as Iver suggests. The patient and family experience has changed during COVID-19, but with a strengthened partnership between patients and healthcare providers working together, we will find the best path forward.

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It’s Time To Take Patient Experience Measurement And Reporting To A New Level: Next Steps For Modernizing And Democratizing National Patient Surveys

Rick Evans, Shari Berman, Esther Burlingame, Stephanie Fishkin

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It has been nearly two decades since the Institute of Medicine named “patient-centered care” as one of six fundamental aims of the US health care system. Since that time, a growing body of research has demonstrated a positive association between patient experience and enhanced clinical outcomes, improved patient safety, and reduction in unnecessary use of medical services. The elevation of patient-centeredness as a national health policy priority also has led to numerous initiatives requiring the use of patient experience measures for public reporting, value-based purchasing, accreditation, certification, and recognition programs. Prominent among these are mandates by the Centers for Medicare and Medicaid Services (CMS) to use the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) surveys for assessing the experiences of patients treated in a wide variety of health care settings, including hospitals, home health care agencies, hospices, and in-center dialysis treatment facilities. Other initiatives requiring the use of CAHPS or other patient experience measures include the Magnet Recognition Program® for excellence in nursing, accreditation programs administered by the Joint Commission for hospitals and the National Committee for Quality Assurance (NCQA) for physicians and health plans, and most recently, hospital rankings published by US News and World Report and the Leapfrog Group.

While standardized CAHPS measures have played an important contributing role in efforts to improve patient experiences through public reporting, accreditation, and value-based purchasing programs, we believe it is time for a comprehensive effort to modernize and democratize all surveys and related data used to assess patient experiences with care. The imperative for modernizing the CAHPS Hospital Survey (HCAHPS) has been articulated recently by several health care industry associations. We agree with these recommendations, particularly those that call for updating the survey content periodically and expanding the use of alternative modes of administration. However, as board leaders and members of the Patient Experience Policy Forum (PXPF), an organization uniquely led by patient and family partners and senior patient experience leaders of hospitals and health systems, we believe that the changes must go further. Below, we highlight the major improvements needed to modernize national patient experience surveys, to improve the content, administration, and analysis, and to democratize them, by making the data more accessible and understandable to all health care stakeholders. These changes should apply to all mandated surveys of patient experiences, not just HCAHPS.

Next Steps For Modernizing The Surveys

Modernization of patient experience surveys is critical to capture current, policy-relevant information on patient needs and priorities. Changes are needed to maintain response
rates sufficient to provide meaningful feedback to health care organizations and to accurately reflect case-mix variations among public- and private-sector providers. We believe that survey sponsors should:

- **Routinely update survey content based on patient, family, and caregiver input:** Changes in health care delivery, technology, demographics, and patient priorities suggest the need to continually update the topics included in patient experience surveys. We believe future additions should be grounded in sound research on topics important to patients, families, and the growing number of informal caregivers assisting people with chronic illness and disabilities. The relevance of new topics must always be explored directly with these audiences to determine how they define a high-quality experience and what types of personal interactions are most salient, meaningful, and important to them. We recognize and appreciate the systematic efforts of CAHPS survey developers to base survey content on this direct evidence. We recommend building on this evidence-based approach by creating a standardized and transparent process for regular review and updating of all patient experience-related measures. CMS recently indicated its intent to explore potential revisions to the content of HCAHPS; we applaud this decision and encourage CMS to consider establishing a regular cycle of review for all mandated surveys.

- **Include patient narratives and comments:** Use of open-ended survey questions to capture patient narratives adds value to public reports for consumers, helps drive and inform improvements by clinicians, and may motivate patients to report on their experiences. We support implementing open-ended question protocols for all CAHPS instruments by building on the Narrative Item Sets developed and tested by the CAHPS Consortium with funding from the Agency for Healthcare Research and Quality (AHRQ). This protocol has been shown to elicit valuable information on patient experience that complements and expands on data obtained from the standardized closed-ended questions on the CAHPS Clinician and Group Survey. The use of evidence-based narrative elicitation protocols also will help to provide more representative and comprehensive comments than are currently available through online rating sites such as Yelp and social media posts, which often are not actionable.

- **Expand modes of administration:** Declining survey response rates, coupled with the cost and respondent burden associated with prevailing modes of survey administration, suggest the need to collect survey data in a way that is less costly, more efficient, and timely. Moreover, survey administration methods should reflect variation in communication preferences across a broad spectrum of demographic cohorts. We strongly support developing and testing new modes of survey
administration, including use of email, interactive voice response (IVR), as well as smartphone and web applications. New, more patient-centered and efficient modes of survey administration will enable more rapid feedback that can enhance quality improvement and more fully represent the experiences of patient populations that have been hard to reach through traditional paper and telephone methods. We applaud the AHRQ and CMS for their ongoing testing related to new modes of survey administration, and we encourage stakeholders to support funding needed to accelerate these efforts.

- **Refine invitation messages:** Survey invitations distributed through both conventional paper and digital modes should be enhanced through careful testing to discover which messages and marketing techniques are most effective in motivating patient responses. Many survey cover letters do not adequately inform patients why their feedback is important or how it can be used to improve care and help other patients make decisions. The language and reading levels of these messages should align with the needs of the patient populations surveyed. Survey sponsors also should explore the use of survey invitations to encourage patients and family members to partner with health care organizations in the co-design of care processes and quality improvement interventions.

- **Level the survey playing field:** Health care organizations treating the most vulnerable and disadvantaged patient populations—such as community health centers, public hospitals, and other safety-net providers—often receive the lowest scores on patient experience surveys. This trend suggests that current case-mix adjustment models may not fully account for all of the patient risk factors beyond providers’ control—such as language, literacy, and cultural barriers—that contribute to lower survey scores. Because safety-net providers typically are underresourced, they are even further disadvantaged when lower survey scores lead to lower reimbursement rates. Data collected from surveys such as HCAHPS over the past decade show differences in scores by region and community types. These data should be examined to see if CMS’s current risk adjustment methodologies need updating to maintain validity and credibility across settings, as well as consistency across public reporting sites (for example, to align with the Hospital Overall Stars risk factor adjustments). Risk adjustment methodologies should be easily replicable by all stakeholders. Policy makers also should explore methods to compensate for inadequacies in case-mix adjustment, such as stratification of providers into peer groups.

Next Steps For Democratizing Survey Data
Democratizing patient experience survey data, so that they are more accessible and transparent, is essential to enable more informed patient decision making and advance continuous quality improvement. We encourage survey sponsors to:

- **Publish vendor-neutral comparative data:** The public survey data sets maintained by CMS, the AHRQ, and other agencies are essential for providing access to comparative benchmarks needed for quality improvement. We commend CMS for recently expanding its published HCAHPS data to include question-level national benchmarks and for announcing recently that it will develop an improved portal through which hospitals can access detailed data. We urge CMS to take further steps to publish question-level HCAHPS data at the hospital level through the portal in the same formats that are used for public reporting. This means providing the full distribution of survey response options, with both percentile and linear mean (that is, average) scores for each question, for every hospital. This will allow for the calculation of national benchmarks that can be vendor-neutral, whether a hospital or system is interested in top box or linear mean benchmarking. This same approach to making granular, question-level benchmarks publicly available should apply to all CMS mandated surveys. This change will enable hospitals, health systems, and consumer groups to make apples-to-apples comparisons across providers, thus ultimately driving quality improvement.

- **Align measurement requirements:** The burden of survey requirements on health care organizations as well as on patients and families could be reduced significantly through more careful alignment of the survey measures required by external regulatory and accreditation organizations. With greater alignment and coordination, fewer surveys would be needed to collect patient experience measures. The result would be a lesser response burden on consumers and a lower cost burden on the hospitals and health systems that finance data collection. Specifically, we suggest coordinating CMS survey requirements with those of the certification, accreditation, and recognition programs sponsored by the ANCC Magnet Recognition Program, the Joint Commission, the NCQA, URAC, and other organizations, so that, wherever possible, all required measures are aligned to create a uniform national data set.

- **Enhance public reporting:** Just as health care organizations need access to comparative benchmark data for improvement, patients and families should have access to more easily accessible and relevant information to support health care decision making. Significant progress has been made in recent years to improve the science of health care performance reporting, yet many of the lessons learned have not been widely adopted by public reporting sites. For example, public reporting currently is based on comparison to other organizations rather than to an absolute
standard of excellence. Reporting relative performance does not tell consumers if an organization truly is improving or if it is merely holding steady while others are declining. Besides improving accuracy and transparency in reporting, survey sponsors should advance strategies to increase consumer awareness and use of public reports that compare the performance of health care organizations to standard benchmarks. Simply including a link to the appropriate CMS Compare site in survey cover letters could help achieve this goal.

The Path Forward

Standardized surveys constitute a necessary but by no means sufficient mechanism for obtaining patient feedback on their health care experiences. Other methods—such as patient/family advisory councils, focus groups, patient shadowing, participation of patients and families on safety committees and task forces, and social media—also are important tools for eliciting essential feedback and perspectives of patients and families. However, the increasing prominence and weight given to standardized patient experience scores in high-stakes initiatives such as public reporting, value-based payment, and provider recognition programs heighten the need for new strategies to modernize and democratize national patient experience surveys. The advent of CAHPS measures has been a powerful force for addressing the needs and preferences of patients and families and for driving improvements in care. We think it is time to take this important work to a new level.

Authors’ Note

The Patient Experience Policy Forum (PXPF), supported by The Beryl Institute, is a broad-based and diverse coalition of patients, family members, caregivers, and health care professionals uniquely led by a balanced board of patient/family partners and senior patient experience leaders. Our purpose and commitment is to advocate for and help shape policy at the national and local levels on issues that directly affect patient and family experience and elevate the human experience in health care. We do so through convening policy forums, educating policy makers, sponsoring advocacy events, providing communication updates, and publishing calls to action.
Let patients speak for themselves on the Biden task force and elsewhere

By Shari Berman Dec. 14, 2020

Ever since President-elect Biden named his Covid-19 task force, advice for improving its makeup has poured in from all quarters. A recent op-ed by two nurses chided Biden to add a nurse to the task force in part because nurses “give voice to patients.”

As a cancer survivor and patient, I have my own voice. So do the millions of patients around the country, whose voices have often been co-opted in national debates and policy forums by nurses, doctors, and others speaking for us.
The Covid-19 task force is an important step in addressing the challenging issues of the coronavirus pandemic. Including experts in public health, physicians, nurses, academics, and commissioners is essential to understanding all perspectives and developing the best plan to move forward. But it doesn’t include a representative from arguably the most important group of health care experts: patients.

Listening to them and knowing what matters most to them is critical when determining how to proceed, rather than others making decisions on their behalf.

I co-lead the Patient Experience Policy Forum in partnership with Rick Evans, the chief experience officer at NewYork-Presbyterian. This group was formed as a two-by-two model in which patient/family leaders and health care leaders work side by side as equal partners because we believe it is essential to understand all perspectives when making policy decisions. Our coalition includes leaders who have dedicated their time to sharing their perspectives and helping improve the patient experience along with patient experience officers and health care executives from hospital organizations across the country.

Patient leaders are engaged by many health care organizations across the country to improve health care to provide insight into what is most important to patients. Partnership and shared decision-making have been shown to correlate with improved quality and safety outcomes, especially when patients are involved in the process from the very beginning. Truly understanding what is important to patients and families, and including their perspectives, is critical to the success of any health care initiative.

Michael Bennick, a physician at Yale New Haven Hospital and board member of the Patient Experience Policy Forum, often describes his patients as experts. “There are two experts in the exam room: me with my scientific knowledge and the patient who knows what is best for themselves and what is important.
We have several patient family advisory councils at Yale New Haven Hospital and one at each of our delivery networks. They are fundamental to the work we do.”

There is no greater champion for improved care, or no advocate for the experience of care, than those who need it or have needed it. Biden’s Covid-19 task force should include the direct voice of patient/family leaders who understand what matters most to those receiving care for Covid-19 or who stand to gain from protective efforts against it. They understand the concerns of patients and families, the barriers they must surmount to access care, and what is most important to them as we all strive for the best outcomes.

The Covid-19 task force has been charged with many objectives, including how to help communities navigate these uncertain times as well as ensuring the equitable distribution of vaccines and treatments. It is essential underserved communities are engaged, especially when distrust and health disparities seem to be at an all-time high among Black and Latino communities. People of color have disproportionately been affected by Covid-19, and their voices should be heard directly to understand what will help them feel safe and cared for in this environment.

Vaccine concerns cut across all socioeconomic and ethnic groups, and who better to engage communities than leaders who understand because they have experienced and lived these concerns directly?

The task force has many action items that would benefit from the contributions and input of patients and family membership. It can serve as an example for how the voices of patients and family members are essential to all we do in health care.

The voice of patients and families is all too often missing from the conversation — especially now as we face the most challenging health crisis of our time. I urge President-elect Biden to include a patient/family leader as part of the Covid-19 team. Including all perspectives makes it possible to
identify and achieve common goals and ensure the most comprehensive vision for the outcomes we all aim to achieve.

Shari Berman is a patient leader and co-chair of the Patient Experience Policy Forum, a diverse coalition supported by The Beryl Institute⁹ that advocates for policies that positively affect patient and family experiences in health care.

About the Author

Shari Berman

shari@shariberman.net¹⁰
@ShariBerman68¹¹

Links

5. https://www.theberylinstitute.org/page/PXPF_Home
7. https://www.statnews.com/privacy/
10. https://www.statnews.com/2020/12/14/let-patients-speak-for-themselves-on-biden-task-force-and-elsewhere/mailto:shari@shariberman.net
11. https://twitter.com/ShariBerman68
This moment in our shared history, as we tackle a global pandemic and face the societal realities of inequity and racism, has shifted the foundations of healthcare forever and revealed the cracks and systemic weaknesses of healthcare globally. There is no normal to which we can, or should, return. Rather, we are called upon to co-create a new existence for healthcare.

For this reason, guided by a global steering team and informed by the voices of our community, The Beryl Institute has undertaken The New Existence Project. This effort will help to define what this new existence will look like; what it will call on us to do in practice, process and policy; and what it will ask of us as people moving healthcare forward.

Grounded in the strategic lenses that shape the experience framework in healthcare and leading us to our community vision – Human Experience 2030 – a focus on The New Existence will align disparate efforts and ensure the human experience at the heart of healthcare flourishes. It will ultimately steer us through this moment to a future we create together.

The New Existence is built on these foundational agreements:

• This work is born from our common experience in this moment
• We are all humans in healthcare and must recognize and act on what impacts us together
• We insist on equity in healthcare
• We commit to working better together, through and beyond this moment
• We will come out of this crisis as better human beings, organizations & systems

To move towards New Existence we suggest a focus on four essential areas presented on the page that follows and offer an associated set of actions aligned with each. Each action item will be supported by a repository of practices and resources to support organizations in their efforts.

About The Beryl Institute

The Beryl Institute is the global community of practice committed to elevating the human experience in healthcare. We believe human experience is grounded in experiences of patients & families, those who work in healthcare and the communities they serve. We define patient experience as the sum of all interactions, shaped by an organization’s culture, that influence patient perceptions across the continuum of care.

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A Framework for Action for the Future of Healthcare

**Care Teams**
Redefine and advance the integrated nature of and critical role patients and their circle of support play on care teams.

**Redefine the care team**
- Identify care team members, including the patient’s family, healthcare providers and the patient’s circle of support.
- Orient care team members, including the patient, to their roles, responsibilities and benefits of being an active part of the care team.
- Include a formal care partner as part of the patient’s care team, and consider peer mentors and cultural brokers and partners.

**Invite and activate partnership**
- Ensure patients and families co-develop the care plan and are an active part of care team interactions and decision-making discussions.
- Identify and act on what matters most to patients, families and the patient’s circle of support.
- Identify and eliminate barriers to effective care team partnership.
- Encourage patients and families to serve in roles beyond their own care journey.

**Commit to care team well-being**
- Celebrate and recognize all those providing and receiving care, and restore joy in work.
- Monitor and manage trauma, burnout and resilience within all care team members.
- Acknowledge and reduce the stigma associated with mental and behavioral health for all care team members.

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**Governance & Leadership**
Reimagine, redefine and reshape the essential role of leadership in driving systematic change.

**Create transparency across the healthcare ecosystem**
- Commit to an integrated strategy for improving patient experience.
- Create a culture of trust.
- Facilitate communication among healthcare, research and advocacy organizations.

**Restore and nurture confidence**
- Formalize outreach programs with patients, families, healthcare professionals and communities.
- Actively seek to understand the concerns and needs of patients, families, healthcare professionals and communities.
- Engage all stakeholders in the co-production, design, implementation and evaluation of new and existing initiatives.

**Transform healthcare in collaboration with diverse voices**
- Engage networks of diverse community leaders as partners to transform the health of the community.
- Address the moral and social determinants of health.
- Take direct action to ensure equity in healthcare.

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**Models of Care & Operations**
Co-design systems, processes and behaviors to deliver the best human experience.

**Co-design intentional, innovative and collaborative systems**
- Create collaborative systems that integrate principles of quality, safety, engagement and well-being.
- Use human-centered co-design to ensure consistent and equitable systems that are personalized and inspire confidence.

**Innovate processes of care to transform behavior**
- Co-design workflows that promote partnership among patients, families, healthcare professionals and communities.
- Solicit and act on feedback at each touchpoint regarding outcomes that matter.
- Develop and apply standardized measures and tools for continuous improvement.

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**Policy & Systemic Issues**
Advocate for equitable institutional, governmental and payor policies, incentives and funding to drive positive change.

**Hardwire human partnership in the healthcare ecosystem**
- Elevate the expertise of patients and the patient’s circle of support.
- Engage patients, families, healthcare professionals and communities in advocacy.
- Remove barriers to accessing care.

**Research, measure and dismantle the structures and systems that lead to disparities**
- Identify where inequity and bias exist within current policies and processes.
- Examine the data to understand the disparities that influence experience and outcomes.
- Dismantle policies and practices that deliver inequitable outcomes.
- Deploy practices that ensure equitable health outcomes.

**Modernize the surveys and democratize the data**
- Diversify the ways in which we capture, hear and listen to patient and family voices across care settings.
- Democratize patient experience survey data to be more transparent, accessible and actionable.
- Modernize patient experience surveys to capture current and relevant information on patient needs and priorities.

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