

SICK, SCARED & SEPARATED FROM LOVED ONES

*Third Edition:
A Pathway to Improvement
in New York City*



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New Yorkers for Patient & Family Empowerment (also known as “Patient & Family”) is a not-for-profit organization that seeks to empower patients and their loved ones in interacting with the healthcare system; strengthen public access to information on patient safety; and improve the quality and safety of healthcare in New York. Patient and Family defines “family” to include the key support persons and loved ones in the patient’s life, as determined by the patient.

The New York Public Interest Research Group Fund (NYPIRG) is a nonpartisan, not-for-profit organization whose mission is to affect policy reforms while training New Yorkers to be advocates. NYPIRG & full-time staff works with residents, produces studies on a wide array of topics, coordinates state campaigns, engages in public education efforts and lobbies public officials.

The Institute for Patient- and Family-Centered Care (IPFCC) advances the understanding and practice of patient- and family-centered care. In partnership with patients, families, and health care professionals, IPFCC seeks to integrate these concepts into all aspects of health care. IPFCC accomplishes its mission through education, consultation, and technical assistance; materials development and information dissemination; research; and strategic partnerships.

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Note: This project measured changes in New York City area hospitals’ policies and website communications regarding family presence and visitation that occurred during the period from April 2016 to July 2017. Between completion of the project and release of this report in January 2018, NYU Langone Health changed the name of NYU Lutheran Medical Center to NYU Langone Hospital - Brooklyn, and made its policy on family presence and visitation consistent with the 24/7 policy in place at NYU Langone’s Tisch Hospital, increasing the number of hospitals in New York City with such policies from 20 to 21.

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SUMMARY OF FINDINGS & RECOMMENDATIONS

Leading advocates for patient- and family-centered care urge that a culture change needs to take place regarding how hospital policy-makers and staff view the patient's support network of family, companions and friends. Instead of labeling a patient's trusted family members as "visitors" or placing arbitrary limits on the times they can be present at the patient's bedside, hospitals should welcome and encourage patient and family member presence and participation, consistent with the patient's wishes.

The patient may trust certain people to act as partners in care, helping to ask questions, discuss treatment options or participate in the planning and actual transition from hospital to home. Such individuals are, for the purposes of this report, deemed "family caregivers," with the term "family" referring to those trusted individuals who, whether related to the patient or not, are designated by the patient to fill this role. They may also be termed "care partners." Other friends may simply provide a cheer-bringing respite from the stress of the hospital experience. Hospital policies should maximize patients' access to their personal support system of loved ones and friends, and treat the members of this support system in a nuanced way to recognize the different roles that such individuals play.

New Yorkers for Patient & Family Empowerment ("Patient & Family") and the New York Public Interest Research Group ("NYPIRG") have twice before examined hospital policies on family and visitor presence and found them wanting. This time, in a project focused on New York City, the Institute for Patient- and Family-Centered Care (IPFCC) provided a training program with follow-up support to help hospitals revisit their policies. Over a third (17) of the hospitals surveyed, as well as a children's hospital located in a hospital surveyed, voluntarily provided representatives who participated in the training. Additionally, three other hospitals that were part of hospi-

tal networks that engaged in the training may have benefited from the networks' central management activities.

This report presents findings and recommendations based on a review of visiting policies and website communications for the 49 acute care hospitals in New York City having 100 or more "staffed beds." It identifies improvements in the policies of several hospitals that participated in the training program. Eight of the ten hospitals whose scores improved over the survey period were participants or, in one instance, part of a hospital network that participated in the IPFCC training and follow-up activity. Among many other hospitals, however, significant, unexplained variations in policy on family caregiver/care partner presence and visitation persist. Six hospitals provided no visiting hours in the morning at all.

This report also found shortcomings in transparency and clarity of messaging for patients, family caregivers/care partners and visitors on nearly all the hospitals' websites. The IPFCC training nevertheless appears to have made a difference with respect to better communication about the designation or role of family caregivers/care partners, or the right to choose visitors, for eight of the nine hospitals whose website scores improved.

Some Hospitals in New York City Provide Many More Hours of Visiting than Others – and Participation in the IPFCC Training Had a Significant Impact on Improvements in Scores

NYPIRG and Patient & Family surveyed each hospital's website twice – in April 2016 and July 2017 – using one ten-point rating system to evaluate the hospital's general (medical/surgical) and ICU visiting hours, and another to evaluate the hospital website's messaging to patients, family caregivers/care partners and visitors regarding

Summary of Findings

being present with the hospital patient. The results were revealing:

- 22 hospitals (45%) received a high score of 8 or better, and 15 of these received a “perfect 10” (many also received an additional bonus point for their policy on children as visitors) based on their policies for general medical/surgical units and ICUs.

- More than half (29) of the hospitals were found to provide 12 or more hours of visiting time per day, with 20 of these hospitals offering 24-hour “open” visitation for general medical/surgical units. Ten others stated or implied that they offered 24-hour “flexibility” specifically for the patient’s family caregiver/care partner.

- Three (3) hospitals received a zero score, meaning the hospital offered no more than a single hour of general visitation in the morning and less than two hours at a time of family caregiver/care partner presence in the ICU.

- Six hospitals were found to provide no visiting hours whatsoever in the morning. A patient of such a hospital could go more than 15 hours without seeing anyone she or he knows, and without anyone who loves the patient being able to observe how the patient is faring. In addition, medical staff – including doctors who often check on hospital patients in the morning – would miss important observations or information that a family member or friend could call to their attention.

The hospitals that participated in the IPFCC training program performed markedly better, as a group, with respect to improved scores than those who did not. Of the ten hospitals whose scores improved during the survey period, eight had participated in the IPFCC training and one hospital was part of a hospital network that did so. Six of these hospitals are part of the NYC Health + Hospitals (H+H) system.

The nine hospitals that had participated in the IPFCC training or were part of a hospital network that did so are marked with an asterisk in the following table, which displays the improvements in scores that occurred.

Improvements in Scores for Policies on Family Caregiver/Care Partner Presence and Visiting

| Hospital | Point Increase | Net Change |
|---|----------------|------------|
| H+H/Bellevue* | 1.5 | 7.5 to 9 |
| Brookdale University Hospital Medical Center* | 1 | 1 to 2 |
| H+H/Coney Island* | 4 | 3 to 7 |
| H+H/Elmhurst* | 9.5 | 1.5 to 11+ |
| Flushing Hospital Medical Center* | 1 | 0 to 1 |
| Hospital for Special Surgery | 10 | 0 to 10 |
| H+H/Jacobi* | 9+ | 2 to 11+ |
| H+H/Lincoln* | 8 | 1 to 9 |
| New York-Presbyterian/Queens* | 6 | 5 to 11 |
| H+H/Woodhull* | 9.5 | 1.5 to 11+ |

This survey also revealed widely divergent rules for child visitors:

- Over a third of the hospitals’ websites (18) were found to explicitly forbid, strongly “discourage” or require prior authorization for visitation by children. One wonders on what grounds a hospital staffer might or might not give prior authorization for a child to visit and how fairly and consistently such decisions are made.

- In contrast, 12 hospitals’ websites (27%) explicitly communicated that children could visit, so long as a supervising adult was with the child.

- The remaining hospital child visitation policies could only be obtained by calling the hospital. Based on telephone calls to facilities, it appears that an additional six hospitals banned or strongly discouraged children as visitors.

Summary of Findings

Inexplicably, the age below which a child's visit was restricted generally ranged from ages 10 to 14 (with one outlier, the Interfaith Medical Center, at age 3), and the age below which a child was required to be supervised ranged from 12 to 16. The basis for making these distinctions is not clear.

A parent, grandparent or sibling should not be deprived of a child's visit without a significant clinical reason, so long as an adult provides supervision as appropriate. As explained in this report, concerns about children as visitors can be addressed and managed.

NYC-Area Hospitals Could Significantly Improve Their Websites' Usefulness to Family Caregivers/Care Partners and Well-Wishing Visitors

A hospital's website is its most public document; it is an important tool for communicating with both prospective patients and visitors. More and more, people today rely on websites for information. This report evaluated the navigability, usefulness and messaging of the hospital websites surveyed on a 10-point scale. Based on this measure, most of the hospital websites are not realizing their potential:

- *No hospital achieved a perfect "10" for its website score. The highest score, achieved by New York-Presbyterian/Morgan Stanley Children's Hospital, was a "9." H+H/Bellevue (which recently revised its website), Lenox Hill Hospital (Northwell Health) and Staten Island University Hospital (Northwell Health) had the third highest scores of 8 points.*
- *Over a third of the hospital websites (17) received a very low website score of only "3" or below, with three of these receiving a score of zero.*
- *On a positive note, 16 of the hospital websites surveyed had clear statements encouraging the patient to designate a person or persons to serve as family caregivers/care partners. Another 14 hospitals had statements that strongly implied this.*

The number of hospitals that clearly declared the family caregiver/care partner as a partner in care was smaller. Seven hospitals met this standard:

*H+H/Coney Island
Lenox Hill Hospital (Northwell Health)
Montefiore Hospital (Moses Campus)
Montefiore Weiler Hsptl. / Jack D. Weiler Hsptl. (Einstein Campus)
Montefiore Wakefield Hsptl (Wakefield Campus)
NY-Presbyterian / Morgan Stanley Children's Hospital
Staten Island U. Hsptl (Northwell Health)*

An additional 15 hospitals' websites contained language that reasonably implied this role.

Most of the websites failed to remind visitors to take important health precautions to improve safety. While hand-washing and other instruction signs usually are posted in the hospital, the website easily can and certainly should provide strong reinforcement and also help people to plan in advance.

Only one of the hospitals examined, New York-Presbyterian/Morgan Stanley Children's Hospital – took the opportunity on its visiting-policy webpage to inform visitors of the need to wash their hands. Fifteen other hospitals included a statement about visitor hand-washing but on a page of the website or patient guide less likely to be viewed by visitors. Over two thirds of the hospital website-posted visiting policies (69%) contained no instruction whatsoever.

Only eight – fewer than one out of five – of the hospital websites warned prospective visitors having a cold, the flu or a cough not to come to the hospital. Mount Sinai St. Luke's, for example, has clear language on its Family and Visitation webpage listing as a ground for restricting visitation a situation in which "Visitors exhibit signs or symptoms of infection (e.g., coughing, runny nose, fever, chills)." While this precaution may seem obvious, many people go to work with cold or flu symptoms.

Summary of Findings

Although the IPFCC training program did not focus on safety communications for visitors, it did address communication regarding the designation and role of the family caregiver/care partner. H+H/Bellevue improved its score by three points, and seven other hospitals' scores improved somewhat – by one, two or 2.5 points – during the survey period. Seven of these eight improved hospitals (marked with an asterisk below) were participants in the IPFCC training or, in one hospital's case, were part of a hospital network that did so. All the website communication improvements related to the designation or role of the family caregiver/care partner, or the patient's right to choose visitors and family caregivers/care partners:

*H+H/Bellevue**
*Brookdale University Hospital Medical Center**
*H+H/Elmhurst**
Hospital for Special Surgery
*H+H/Jacobi**
*H+H/Lincoln**
*New York-Presbyterian/Queens**
*H+H/Woodhull**

All the hospitals surveyed now comply with the patient's right to choose who can visit.

Even better, 70% (34) of the hospital websites take the responsible step of affirmatively and clearly explaining this important right to patients (compared with only 10 websites of New York City area hospitals doing so in 2013). 🏠

Compliance with the Patient's Right to Choose Who Can Be at Bedside

Federal regulations pursuant to Medicare and Medicaid as well as a New York State regulation mandate that hospital patients have the right to choose who can visit. The patient's choice may include family members, a domestic partner (regardless of gender), a trusted care aide or other friends.

When Patient & Family and NYPIRG last conducted a survey on right-to-choose language in 2013, six hospitals in New York City had language that conflicted with these regulations, such as outdated "immediate family only" language. The current survey found that none of the hospitals has conflicting language.

1. See Mount Sinai St. Luke's webpage on Family and Visitation, <http://www.mountsinai.org/locations/st-lukes/your-visit/planning>, accessed July 2017.

RECOMMENDATIONS

Recommendation #1: 24-hour Presence

If a hospital allows an adult patient's family caregiver/care partner to be present any time or to stay overnight, its website-posted policy should state this clearly.

Recommendation #2: Morning Hours

Hospitals that do not permit 24-hour presence for a family caregiver should at least provide a substantial amount of visiting time in the morning, and should begin a process to review and change restrictions on family caregiver presence.

Recommendation #3: Designation of Family Caregiver Person

The hospital's website-posted policy should specifically encourage patients to designate one or more family caregivers/care partners and explain what the role entails.

Recommendation #4: Care Partner Role of Family Caregiver/Support Person

The hospital's website-posted policy should clarify that a patient-designated family caregiver person is not merely a well-wishing visitor but a partner in care, and part of the care team for that patient.

Recommendation #5: Children as Visitors

Hospitals that prohibit or substantially restrict children as visitors should consider adopting a more accommodating policy. Policies should address unwanted behavior as needed, but not identify "unwanted" people.

Recommendation #6: Health Advisories

The hospital's website-posted policy should:

- *Explicitly instruct that anyone with a cold, rash, fever, influenza or other communicable disease should not visit the hospital. Many people do not think of a cold as an illness.*
 - *Remind family caregivers/care partners and visitors to wash their hands if entering or leaving the patient's room.*
 - *Disclose any restrictions or guidance (such as advising consultation with the patient's doctor or nurse) on bringing in latex balloons, flowers or food.*
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Recommendation #7: Transparency and Consistency

Hospitals should compare their written policies on family caregiver/care partner presence and visiting with actual practices. Policies that are outdated or routinely ignored or countermanded should be examined. (A policy that is ignored, or for which "exceptions" are very frequently made, is not really a policy.) All communications of the policy must be consistent. All staff and volunteers in administration (including those who respond to telephone inquiries), patient intake, and the "floor" should know and properly communicate and carry out the policy.

Recommendation #8: Involving Stakeholders

In developing policies on family caregiver/care partner presence and visiting, hospitals should obtain input not only from administrators, but also from front-line staff involved in patient care and social services, patients and their family caregivers/care partners, patient and family advisory councils, and health consumer advocates. 🏠

BACKGROUND:

The Benefits of Policies that Maximize the Presence of Family Caregivers & Facilitate the Presence of Well-Wishing Visitors

“We cannot coherently advocate engagement while employing clinician centered visitation. Restrictive visiting hours reflect a brutish paternalism that has no place in contemporary medicine. Such policies strip patients of their relationships—the core meaning of their lives—when life is most threatened.”²

Samuel M. Brown, MD, The BMJ, 2015

Research has, for over two decades, identified substantial benefits that occur when hospitals maximize patients’ access to their personal support system of loved ones and friends.³ For example, research increasingly indicates that for many older patients, hospitalization for acute or critical illness is associated with reduced cognitive function.⁴ Family caregivers/care partners may be much more keenly aware of a change in cognitive function and thus can be a valuable information resource for hospital staff. Yet, many hospital policies still limit patient access to loved ones and friends through restrictive “visiting hours,” and this remains true in New York City.

When Patient & Family and NYPIRG examined current hospital policies in New York City on family presence and visitation, two factors immediately became apparent:

- *First, many hospital policies still are inconsistent with research findings on the benefits of family caregiver/care partner presence and visitation.*
- *Second, many hospital policies still fail to differentiate between the patient’s designated family caregivers/care partners, and other individuals who are well-wishing visitors.*

For the purposes of this report, the term “family caregiver” or “care partner” is used to describe individuals, whether related to the patient or not, who have been identified by the patient as sup-

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2. S. M. Brown, “We Still Lack Patient Centered Visitation in Intensive Care Units,” *The BMJ*, 350, h792, (2015).
 3. K. Giuliano, et al., “Families First: Liberal Visitation Policies May Be in Patients’ Best Interest,” *Nursing Management* 31(5): 46, 48-50 (2000); and R. Gasparini, et al., “Increased Family Presence and the Impact on Patient- and Family-Centered Care Adoption,” *The Journal of Nursing Administration*, 45(1), 28-34, (2015).
 4. W. J. Ehlenbach, et al., “Association Between Acute Care and Critical Illness Hospitalization and Cognitive Function in Older Adults,” *JAMA*, 303(8):763-770 (2010) (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2943865/>)

Background

port persons whom the hospital should consider to be partners in care for the patient.⁵ The term “well-wishing visitor” refers to other family members or friends who have not been designated by the patient to play such an involved role but nevertheless are individuals the patient would like to see from time to time during the hospital stay. Both family caregivers/care partners and well-wishing visitors can benefit a patient in important ways, but hospital policies should recognize their different roles.

Federal Requirements for Policies on Family Caregiver/Care Partner Presence and Visiting

Federal regulations issued in 2010 by the Center for Medicare and Medicaid Services (“CMS”) establish that patients have a right to have whomever they choose at bedside, limited only by specific clinical considerations. Hospitals must disclose in a written hospital policy their reasons for limiting the rights of patients to the presence of family/support persons or visitors. A hospital must:

*...have written policies and procedures regarding the visitation rights of patients, including those setting forth any clinically necessary or reasonable restriction or limitation that the hospital may need to place on such rights and the reasons for the clinical restriction or limitation.*⁶

The regulations squarely place the burden on hospitals to provide justification for restricting visits. The notice of final rule-making for the federal rules provided three examples of instances in which hospitals might impose clinically reasonable restrictions: “When the patient is undergoing care interventions; when there may be infection control issues; and when visitation

may interfere with the care of other patients.”⁷ CMS also noted that disruptive behavior, a patient’s need for rest or privacy, and other reasons for restrictions also may be considered.⁸ Nevertheless, CMS states unequivocally:

We remind hospitals ... that, when establishing and implementing visitation policies and procedures, the burden of proof is upon the hospital ... to demonstrate that the visitation restriction is necessary to provide safe care.”⁹

In other words, the presence of family caregivers/care partners and visitors is considered a patient’s right, rather than a hospital-granted privilege, and hospitals must justify in writing any rules restricting it. A statement of reasons for any restrictions must be provided within the visiting policy.

The patient’s desires and needs must drive the plan for family caregiver/care partner presence and well-wishing visitation. The concept of “open” visiting, a term often used to describe 24-hour visiting policies, is not to flood the patient with visitors at all hours regardless of what the patient wants or needs. As Dr. Don Berwick, former Director of CMS, explains, “The goal is not universal implementation of unrestricted ... visiting policies, but rather the achievement of patients’ control over the circumstances of their own care.”¹⁰ A study of patients in a hospice facility, for example, noted that it is important for patients to have control over the number of visitors, the timing of visits, and how long visitors stay, and that staff should involve patients in decisions about visitors whenever possible.¹¹

A visiting plan may include not only who can be present at bedside, but also who cannot be present, based on the patient’s preferences. It may include

5. A family caregiver (support person) may or may not be the same person who holds the patient’s “health care proxy,” a document that allows the patient to designate a trusted individual to make decisions on medical care if the patient loses the ability to do so (http://www.health.ny.gov/professionals/patients/health_care_proxy/). Also, a patient may have more than one family caregiver.

6. 42 CFR Part 482.13(h); see also Part 485.635(f).

7. See 75 F.R. 70831, 70839 (Nov. 19, 2010) and 75 FR 29479 (May 26, 2010).

8. 75 FR 70831, 70839 (Nov. 19, 2010).

9. Id.

10. D. Berwick and M. Kotagal, “Restricted Visiting Hours in ICUs: Time to Change,” *JAMA* 292(6):736-37 (Aug. 11, 2004).

11. Helen Gray, et al., “Visiting All Hours: A Focus Group Study on Staff’s Views of Open Visiting in a Hospice,” *Internatl J Palliative Nurs*, 17(11):552-560 (2011).

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“quiet times” or times when the patient does not want anyone else present. It may be revised as the patient's needs change or a problem arises. The purpose is to devise, by working cooperatively with the patient, a flexible plan that meets the patient's desires and needs without arbitrary limitation.

Where patients have roommates, of course, the patient's plan must include consideration for a roommate's need for rest and quiet, but a roommate's needs should not require a patient to give up the right to the presence of a family caregiver.

Important Roles of the Family Caregiver/Care Partner

IPFCC advocates that the family must be “respected as part of the care team,”¹² rather than being excluded at important stages in care. IPFCC, together with the American Hospital Association co-produced a resource guide for hospitals that asserts:

*Hospitals that practice patient- and family-centered care welcome and encourage patient and family member participation in care and care planning. They do not label family members as “visitors” and do not limit the hours they may spend at the patient's bedside. They encourage patients and family members to participate in rounds and other decision-making processes. Staff prepare and support patients and families to participate in care at a level they choose.*¹³

Even hospitals that do not have a specific policy on this matter often informally make such a differentiation in practice. When this occurs, it is a tacit recognition of the fact that roles are different for general well-wishers compared with a patient's family caregivers/care partners.

The Joint Commission, which accredits hospitals¹⁴ and educates the public on how to help prevent medical errors, urges patients to:

*Ask a trusted family member or friend to be your advocate (advisor or supporter). Your advocate can ask questions that you may not think about when you are stressed. Your advocate can also help remember answers to questions you have asked or write down information being discussed. Ask this person to stay with you, even overnight, when you are hospitalized. You may be able to rest better. Your advocate can help make sure you get the correct medicines and treatments.*¹⁵

Also, the Commission's evaluation of hospitals considers whether the hospital allows a family member, friend or other individual to be “present with the patient for emotional support during the course of stay.”¹⁶ The Commission thus clearly views the presence of patient-designated family caregivers/care partners as both a health benefit and a patient right.

While some hospitals prefer that family caregivers/care partners leave during shift changes or “rounds,” these are in fact important times for them to be present. Many serious problems in healthcare can be traced to poor coordina-

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12. Institute for Patient- and Family-Centered Care, “Changing Hospital ‘Visiting’ Policies and Practices: Supporting Family Presence and Participation” (August 2010).
 13. American Hospital Association and Institute for Family-Centered Care, Strategies for Leadership: Advancing the Practice of Patient- and Family-Centered Care (Sept. 2004) (<http://www.aha.org/content/00-10/resourceguide.pdf>, accessed July 19, 2017).
 14. The Joint Commission is a not-for-profit entity that accredits and certifies nearly 21,000 health care organizations and programs nationwide. See https://www.jointcommission.org/about_us/about_the_joint_commission_main.aspx (accessed July 19, 2017).
 15. The Joint Commission, “Help Prevent Errors in Your Care” (A “Speak Up” educational brochure for the public) (<http://www.jointcommission.org/assets/1/6/speakup.pdf>, accessed July 19, 2017).
 16. The Joint Commission, “R3 Report (Requirement, Rationale, Reference): Patient-Centered Communication Standards for Hospitals,” Issue 1 (Feb. 9, 2011) (https://www.jointcommission.org/r3_issue1/, accessed July 19, 2017). See, The Joint Commission, Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals (2010), which provides recommendations for meeting patient-centered communication standards (<http://www.jointcommission.org/assets/1/6/ARoadmapforHospitalsfinalversion727.pdf>, accessed July 19, 2017).

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tion or inadequate information transfer, especially during transitions from one care provider to another.¹⁷ A patient's family caregiver/care partner can help ensure that key information is transmitted during these crucial periods. Indeed, Partnership for Patients, a CMS-funded program in which approximately 80% of U.S. hospitals are organized in Hospital Improvement Innovation Networks (HIINs) to seek to make care safer, less costly, and more reliable, identifies partnering with patients and families in change-of-shift reporting and rounds as an essential practice and includes it as a metric for evaluation.¹⁸

Family caregiver/care partner presence is beneficial not only in general medical/surgical units but also in the ICU, where it can “foster communication, understanding and collaboration between the family and health care providers.”¹⁹ Dr. Don Berwick, a former head of the federal Centers for Medicare and Medicaid, has long recommended accommodation of family caregivers/care partners in ICUs.²⁰ The findings of a recent literature survey reviewing 22 articles from 1997 through 2013 regarding family presence in the ICU, back up Dr. Berwick's recommendation, stating:

Several studies show that the presence of family and friends increases the satisfaction of patients and their family due to promoting the guarantee of patient care. This is especially significant when

*patients are intubated and cannot speak. The presence of visitors can improve the personnel's communication, understanding, care and satisfaction.*²¹

CMS, when issuing its regulations for policies on family presence and visitation, summarized the findings of an article in the *Journal of the American Medical Association*²² on family presence in the ICU, stating that “available evidence indicates that hazards and problems regarding open visitation are generally overstated and manageable,” and that such visitation policies “engender trust in families, creating a better working relationship between hospital staff and family members.”²³ Subsequently, a study of the transition from a more restrictive to less restrictive policy on family caregiver/care partner presence in an ICU found that patient satisfaction increased while nurses did not report any increase in interference with medical care.²⁴ The American Association of Critical-Care Nurses specifically recommends accommodating family caregiver/care partner presence during resuscitation and invasive procedures, stating that such presence is reported to “improve medical decision making, patient care, and communication” with patients' family while resulting in “[n]o patient care disruptions” and “[n]o negative outcomes during family presence events.”²⁵

In contrast, unnecessary restrictions create unnecessary risks. A study comparing ICU patients'

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17. See, AHRQ Web Morbidity & Mortality Rounds on the Web, “Dangerous Shift – Commentary by Emily S. Patterson, Ph.D.” (Nov. 2008) (<https://psnet.ahrq.gov/webmm/case/188/dangerous-shift>, accessed July 19, 2017); Leora Horwitz, et al., “Consequences of Inadequate Sign-out for Patient Care,” *Arch Intern Med* 168(16):1755-60 (2008). See also, IOM, *Crossing the Quality Chasm: A New Health System for the Twenty-first Century* (Washington, DC: National Academies Press, 2001); E. Coleman and R. Berenson, “Lost in Transition: Challenges and Opportunities for Improving the Quality of Transitional Care,” *Annals of Internal Med.* 141(7):533-36 (2004); and Elliott Fisher, et al., “Creating Accountable Care Organizations: The Extended Hospital Medical Staff,” *Health Affairs* 26(1):w44-w57 (Project HOPE, published online, 2007).
 18. The metric for Patient and Family Engagement (“PFE”), authentic partnerships with patients and families, is, “The Hospital conducts shift change huddles and bedside reporting with patients and family members in all feasible cases.” HIINs, “Patient and Family Engagement.” (<https://healthinsight-hiin.org/patient>, accessed 7/20/2017).
 19. Mary Beth Flynn Makic, et al., “Evidence-based Practice Habits: Putting More Sacred Cows Out to Pasture,” *Critical Care Nurse*, 31(2):38-62, 51 (April 2001).
 20. D. Berwick and M. Kotagal, *supra*.
 21. Shiva Khaleghparast, et al., “A Review of Visiting Policies in Intensive Care Units,” *Glob J Health Sci* 8(6):267-276 (June 2016).
 22. D.M. Berwick and M. Kotagal, *supra*.
 23. CMS, “Medicare and Medicaid Programs: Changes to the Hospital and Critical Access Hospital Conditions of Participation to Ensure Visitation Rights for All Patients,” 75 FR 70831 (regarding 42 CFR Parts 482 and 485).
 24. Diane Chapman, et al., “Satisfaction with Elimination of all Visitation Restrictions in a Mixed-Profile Intensive Care Unit,” *Am J Crit Care* 25(1):46-50 (Jan. 2016) (<https://www.aacn.org/docs/cedmedia/A1625013.pdf>, accessed July 16, 2017).
 25. C. Guzzetta, RN, PhD, FAAN, “AACN Practice Alert: Family Presence During Resuscitation and Invasive Procedures,” *Critical Care Nurse* 36(1):e11-e13 (Feb. 2016) (approved by AACN Clinical Resources Task Force, 2015) (<http://ccn.aacnjournals.org/content/37/1/84.full>, accessed July 16, 2017).
 26. Stefano Fumagalli, et al., “Reduced Cardiocirculatory Complications with Unrestrictive Visiting Policy in an Intensive Care Unit,” *Circulation*, 112:946-952 (2006).

Background

anxiety under restricted and unrestricted visiting policies found that unrestricted policies reduced the patient's "anxiety score" significantly, and *major cardiovascular complications were more frequent under the restricted visitation policy*.²⁶ Also, such restrictions deprive hospital staff of important observations and helpful knowledge that those who are close to a patient often can provide, such as knowledge of the patient's full range of medications.

Overnight stays, moreover, should be accommodated, based on the patient's wishes. A 2015 article in the *Journal of Clinical Outcomes Management* reported the very positive experiences of three hospitals that participated in IPFCC's international campaign, *Better Together: Partnering with Families*. After implementing policies supporting family caregiver/care partner presence and participation, these hospitals found that family presence increased patient satisfaction and reduced hospital-acquired infections. In the first year of its new "welcoming" policy, one hospital had more than 7,000 family caregivers/care partners stay overnight with loved ones – with no reported increase in security events.²⁷

Finally, family caregivers/care partners play a critical role in hospital discharge planning. They are reservoirs of important information that hospital discharge planners should have to do their jobs properly. Failing to use this resource can have adverse effects. The United Hospital Fund, in a 2014 report that included the results of interviews of 137 patients who had been readmitted, or their family caregivers/care partners, found that 43% of patients and caregivers were not given contact information to use if they had questions after discharge, and almost one quarter did not

receive instructions at discharge about diet and activity. The respondents indicated generally that readmission occurred because of lack of awareness about how to manage the illness at home, inability to follow diet-exercise recommendations or lack of family or professional caregiver support.²⁸

Integrating family caregivers/care partners into patient discharge planning, in contrast, has been found to be highly beneficial. A 2017 study regarding older adult patients concluded that integrating caregivers into discharge planning resulted in:

- 25% reduction in risk of elderly patient being readmitted to hospital within 90 days; and
- 24% reduction in risk of being readmitted within 180 days.²⁹

In response to the AARP/UHF study that showed that nearly half of family caregivers reported doing medical/nursing tasks after hospital discharge but had little or no training,³⁰ New York State (and several other states) have enacted the Caregiver Advise, Record and Enable (CARE) Act. New York's law, which took effect in April 2016, requires hospitals to ask patients, upon admission, if they wish to designate a family caregiver/care partner. If they do, then they are asked to sign a written consent for sharing medical information with that individual. The hospital must then consult with this individual regarding his or her ability carry out post-discharge care tasks; notify this individual about the discharge date; and provide instruction to this individual on how to perform post-discharge care tasks at home. The United Hospital Fund produced a "CARE Act Toolkit" to help facilitate implementation of the law,³¹ as well as a guide to help patients and family caregiv-

27. Deborah L. Dokken, et al., "Changing Hospital Visiting Policies: From Families as "Visitors" to Families as Partners," *J Clinical Outcomes Management* 22(1), 29-36, (2015) (<http://www.jcomjournal.com/reports-from-the-field-changing-hospital-visiting-policies-from-families-as-visitors-to-families-as-partners/>, accessed July 27, 2017).

28. H. Jalon and E. Heagerty, United Hospital Fund, *Reducing Hospital Readmissions: Lessons from a Multi-Hospital Initiative* (United Hospital Fund, 2014) (<http://www.uhfnyc.org/publications/881008>, accessed July 20, 2017), pp. 2-3.

29. Rodakowski, et al., "Caregiver Integration During Discharge Planning for Older Adults to Reduce Resource Use: A Meta-analysis," *J American Geriatrics Soc* (2017) (<http://onlinelibrary.wiley.com/doi/10.1111/jgs.14873/full>, accessed July 17, 2017) (a meta-analysis of several studies).

30. Susan Reinhard, Carol Levine, and Sarah Samis, "Home Alone: Family Caregivers Providing Complex Care" (Oct. 2012) (<http://www.uhfnyc.org/publications/880853>, accessed Oct. 27, 2017).

31. United Hospital Fund, "Implementing New York State's CARE Act: A Toolkit for Hospital Staff" (Feb. 2017) (<http://www.uhfnyc.org/publications/881178>, accessed Sept. 12, 2017).

Background

ers/care partners understand the law and their role in its implementation.³²

Successful implementation of New York’s CARE Act will depend in part on addressing problem areas identified by the United Hospital Fund in a webinar program and poll involving nearly 200 hospital staff from around the State. When hospital staff were asked to identify the most significant challenges in implementing the CARE Act, the most common response was “Patient unwilling to name a caregiver” (51%). Some other high priority concerns were: “Patient without stable residence or support system” (46%); “Named caregiver unwilling or unable to perform required tasks” (43.5%); and insufficient time to perform the required post-discharge instruction (43.5%).³³ A policy that welcomes supportive family members and well-wishing visitors based on the patient’s preferences may facilitate opportunities for further communication with the patient and the patient’s support network that could help to identify an individual whom the patient could designate to fill the CARE Act role.

Importance of the Well-Wishing Visitor

Attention must be paid not only to the engagement of family caregivers/care partners, but also to the general “visiting hours” of a hospital for well-wishing visitors. Such visitors can help a patient to avoid or minimize the “disorientation” that can result from hospital surroundings, keeping the patient in touch with even such basic factors as the passage of time. Unnecessary restrictions can reduce these benefits.

Also, as noted above, some patients do not have, or are reluctant to designate, any family caregiver/care partner, yet do have well-wishing visitors. Under such circumstances, well-wishing visitors can play a helpful role for such a patient. Indeed,

one or more of them may ultimately “step up,” with the patient’s consent, to play either some or all of the more responsible roles of a family caregiver/care partner.

The Gap Between Written Policies and Actual Practices

In discussions of visiting policies with nurses and former patients or visitors, the most common comments were, “But nobody really follows the policy,” and, “If you ask the nurses, they can make an exception.” It is certainly true that, while the hospital may have restrictive rules, nursing staff often use their own judgment and allow more flexibility.

The gap between written policies and implementation practices, however, is an important issue in and of itself. While an individual patient can benefit when the hospital accommodates a request for “flexibility,” a policy that is routinely “honored in the breach” is unfair for the patients who do not benefit from this accommodation. A patient or loved one may not even attempt to ask for flexibility because he or she may, for example:

- *Feel overwhelmed or intimidated by the institution;*
- *Fear that it may annoy the people providing medical care to the patient;*
- *Have a personal or culturally-embedded propensity against challenging rules;*
- *Not realize that such flexibility might be available; or*
- *Have difficulty speaking fluent English.*

32. United Hospital Fund, “New York State’s CARE Act: A Guide for Patients and Family Caregivers” (Feb. 2017) (<https://www.uhfnyc.org/publications/881201>, accessed Sept. 12, 2017).

33. Carol Levine, United Hospital Fund, “Implementing the CARE Act: What’s Working? What’s Not?” (June 12, 2017) (<https://www.uhfnyc.org/news/881224>). An additional high priority concern was what to do when the patient is conscious but unwilling to name a caregiver because of cognitive impairment” (35.9%); the CARE Act does not provide procedures to address this situation in which a patient is conscious but cognitively impaired.

34. Patient & Family and NYPIRG, *Sick, Scared and Separated from Loved Ones* (August 2012).

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The result could be an unintended yet *de facto* disparity in patient care. Hospital management likely will not know to what extent its staff is dispensing such case-by-case flexibility fairly and without any favoritism, whim or negative pre-judgment. Such a non-transparent approach leaves open the worrisome possibility that the exercise of such “discretion” could occasionally be arbitrary or discriminatory. Also, patients or their primary support persons may feel resentful if they see privileges granted to other family caregivers/care partners or visitors that they have not received, regardless of the hospital staff’s good intentions.

While some flexibility should always be available to deal with unusual circumstances on a case-by-case basis, this report recommends that hospitals compare their written policies with actual practice, and update their policies so that the rules are more transparent and more broadly applied.

Prior Reports on Family Caregiver/Care Partner Presence and Visiting Policies in New York Hospitals

Patient & Family and NYPIRG have issued two reports on hospital visiting policy prior to conducting this research. The first report, issued in 2012, examined visiting hours for medical/surgical units only, and addressed acute care hospitals throughout New York State that had 200 or more staffed beds. On a 10-point scale, only four of the 99 hospitals surveyed received a “perfect 10,” and only seven hospitals received a high score of “9” or “8.” Conversely, four hospitals received a zero score, meaning the hospital offered fewer than eight hours of daily visiting time and provided no notice of an opportunity for flexibility. A surprising 22% provided no visiting hours in the morning and failed to disclose any potential for flexibility on that policy, even for a patient’s support person.³⁴

Regarding website accessibility and helpfulness, which was also ranked on a 10-point scale in 2012, no hospital website received a perfect “10”; the highest score was “8,” achieved by just eight hospitals. In contrast, 27% of the hospitals had received a website score of only “3” or lower, and seven of these had received a score of zero. (Note that in 2013, a study published in the *Critical Care* journal of 606 hospitals throughout the United States found that over two-thirds had restrictive general hospital visiting policies and 90% of the hospitals’ ICUs had restrictions.)³⁵ The report also found that 30% of the hospitals’ websites contained statements that directly conflicted with the patient’s legal right, pursuant to federal and state regulation, to choose who can be present at bedside, and many of the other hospitals’ websites contained language that implied that the hospital could exclude visitors who were not relatives.

The second report, issued by Patient & Family and NYPIRG with Lambda Legal in 2013, again surveyed those same acute care hospitals throughout New York State, but focused solely on the issue of the patient’s right to choose who can be present, whether as a family caregiver/care partner or as a well-wishing visitor. More than one-third of the hospitals targeted in 2012 had since improved their website statements regarding the patient’s right to choose visitors. Unfortunately, 17% of the hospitals examined still had language on their websites that directly conflicted or was inconsistent with the federal rule, and only 36% of the websites affirmatively informed viewers of this important right.³⁶

Approach of This Report: The Role of the IPFCC Training Program

The review described in this report focused specifically on New York City’s “acute care” hospitals – facilities that provide inpatient medical care and related services for surgery, acute medical conditions or injuries (usually for a short-term illness

34. Patient & Family and NYPIRG, *Sick, Scared and Separated from Loved Ones* (August 2012).

35. V. Liu, et al., “Visitation Policies and Practices in US ICUs,” *Critical Care* 17(2):R71 (2013).

36. Patient & Family and NYPIRG, *Sick, Scared and Separated from Loved Ones II* (August 2013) (available at https://www.lambdalegal.org/sites/default/files/publications/downloads/sick-scared-separated-2_2013.pdf).

Background

or condition) – having 100 or more staffed beds. It evaluated policies on family presence and visiting for general medical and surgical units and for the Intensive Care or Critical Care Unit (“ICU” or “CCU”).³⁷

The measuring tools originally developed for the 2012 report were adjusted to include policies for the ICU (or CCU) and, in consultation with IPFCC, to include information on the hospital’s communications regarding patient-identified family caregivers/care partners and their role as partners in care.

The researchers conducted a preliminary survey in April 2016 of information posted on the hospital website regarding policies for family caregiver/care partner and visitor presence.³⁸ Where visiting hours were not posted or appeared unclear,³⁹ a telephone call was made to the hospital’s main switchboard to request the information. If the supplementary information was provided by an individual rather than on an automated pre-recorded telephone message, a second call was made at another time to confirm the information received by telephone. The results were tabulated and analyzed.

Shortly before this initial survey, 17 of the hospitals surveyed, as well as a children’s hospital located in a hospital surveyed, had chosen to participate in a training offered by IPFCC.⁴⁰ This one-day event, held on March 22, 2016 at the New York Academy of Medicine, was attended by 75 participants, including hospital personnel, patient and family advisors, and community-based advocacy organizations. The participating hospitals had completed an online Organizational Self-Assessment describing their “visiting” policies and practices. After the training event, many of the hospitals engaged in a series of follow-up “coaching calls” to discuss their efforts to review and revise their policies.

Each hospital that chose to participate fully in IPFCC’s training program not only received that training and follow-up support but also received the benefit of information on the results for its facility from the initial screening of websites regarding the parameters of its policy and the quality of its website communications. This allowed the hospital a distinct advantage regarding the ability to improve its policy and website communications prior to the final screening.

A second survey was conducted in July 2017 to identify any changes in hospital policies that had occurred in the interim. These results were tabulated and analyzed – see Appendix C, Summary of Scores and Visiting Hours of NYC-based Acute Care Hospitals (100 or more beds) – and the performance of hospitals that participated in the training were compared to those of hospitals that did not participate.

The 10-point scoresheet for family presence and visiting policies (with one additional bonus point available if the hospital accommodated children as visitors without age restrictions other than a requirement of adult supervision) included such factors as the availability of 24/7 visitation for family caregivers/care partners, the availability of morning hours of visitation, and the period allowed for ICU visitation (some require that each visit be only for a certain length of time). The 10-point scoresheet for website communications included such factors as the clarity of statements about the patient’s right to choose visitors and to designate individuals that would serve as family caregivers/care partners, as well as statements about the role of such family caregivers/care partners as partners in care. It also examined the extent to which the hospital was using its website as a communication avenue to family caregivers/care partners and visitors regarding hand-washing hygiene, avoiding coming to the hospital with a cold, and other matters. ■

37. This report does not address Maternity Unit policies.

38. The websites were examined for the purposes of this report in April 2016, and were reviewed again in July 2017.

39. For examining visiting hours, information from downloadable “Patient Guides” from the hospital website was considered, even if the guide was directed to the patient’s rather than visitor’s attention. For evaluating website usefulness for visitors, information in a “Patient Guide” only received half “point” consideration if located on a page not devoted to visitor policy.

40. Three additional hospitals from Long Island participated: St. Charles Hospital, John T. Mather Memorial Hospital, and South Nassau Communities Hospital.

Improvements in Policies — and Disappointments

Several acute care hospitals currently operate in New York City with very flexible visiting policies. On a 10-point scale, points were awarded based on the total hours of general visiting time; availability of morning general visiting hours; notice of potential accommodation in general visiting hours; notice of availability of 24-hour visitation at least for family caregivers, and length of visiting periods allowed in the ICU (See Appendix A, Hospital Score Sheet Form: NYC-Area Hospital Policies on Family Caregiver Presence and Visiting). A bonus point was awarded if the hospital accommodates children as visitors.

Of the hospitals surveyed, 15 received a “perfect 10” (or more, if awarded a bonus point). The hospitals receiving this perfect 10 score were:

| | |
|--|-------|
| <i>H+H/Elmhurst</i> | 11+ |
| <i>Hospital for Special Surgery</i> | 10 |
| <i>H+H/Jacobi</i> | 11+ |
| <i>H+H/Metropolitan</i> | 10+ |
| <i>New York-Presbyterian/Allen Hospital</i> | 11 |
| <i>New York-Presbyterian/ Columbia University Medical Center</i> | 11 |
| <i>NY-Presbyterian/Lower Mnhtn Hospital</i> | 11 |
| <i>NY-Presbyterian/ Morgan Stanley Children’s Hospital</i> | 11+ |
| <i>New York-Presbyterian/Queens</i> | 11 |
| <i>New York-Presbyterian/ Weill Cornell Medical Center</i> | 11 |
| <i>H+H/North Central Bronx Hospital</i> | 11 |
| <i>NYU Hospital for Joint Disease</i> | 10.5+ |
| <i>NYU Langone’s Tisch Hospital</i> | 11 |
| <i>H+H/Queens</i> | 10 |
| <i>Staten Island U. Hspt(Northwell Health)</i> | 11+ |

The other high scorers (8 or 9 points) included:

| | |
|---|----|
| <i>H+H/Bellevue</i> | 9 |
| <i>Brooklyn Hospital Ctr (Downtown Campus)</i> | 8+ |
| <i>L.I. Jewish Forest Hills Hsp. (Northwell Health)</i> | 9+ |
| <i>H+H/Harlem</i> | 9+ |
| <i>Lenox Hill Hospital (Northwell Health)</i> | 9+ |
| <i>H+H/Lincoln</i> | 9 |
| <i>Mount Sinai Brooklyn</i> | 9+ |

Some hospitals, in contrast, had posted policies that significantly restricted patients’ access to family and other trusted people. Three hospitals received a score of zero, which could only occur if the hospital offered less than two hours of morning visiting time and less than two hours at a time of visitation in the ICU: Under these hospitals’ website-posted policies, general visiting time did not start until 11:00 a.m. or later. Also very disappointing is the fact that over a third of the hospitals (17) scored only between 0 and 3. (See Appendix C, Summary of Scores and Visiting Hours of NYC-based Acute Care Hospitals [100 or more beds].)

A. Hospital Visiting Hours Vary from 24-hour/Open Visitation to Just Eight Hours

Several hospitals’ websites emphasized the importance of visits to patients, yet their approaches to visiting varied widely, and the inconsistency was striking.

- *More than half (29) of the hospitals provided 12 or more hours of visiting time per day.*

- *20 hospitals clearly offered a general 24-hour “open” visiting policy. These “open visitation” or patient-accommodating hospitals include:*

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The Brooklyn Hospital Center (Downtown)
Lenox Hill Hospital (Northwell Health)
Long Is. Jewish Forest Hills Hosp. (Northwell)
H+H/Elmhurst
H+H/Harlem
H+H/Jacobi
H+H/Metropolitan
H+H/North Central Bronx
H+H/Queens
Hospital for Special Surgery
New York-Presbyterian/Allen Hospital
New York-Presbyterian/Columbia Univ Med Center
New York-Presbyterian/ Lower Manhattan Hospital
NY-Presbyterian/ Morgan Stanley Children's H.
New York-Presbyterian/Queens
New York-Presbyterian/Weill Cornell Med. Center
NYU Hospital for Joint Diseases
NYU Langone's Tisch Hospital
Richmond Univ. Medical Center (Mount Sinai affil.)
Staten Island University Hospital (Northwell Health)

- Ten others stated or implied that they offer 24-hour “flexibility” for the patient’s family caregiver/ care partner.

- In contrast, 13 of the hospitals, based on statements made on their websites or by telephone, offered only nine hours or slightly less of visiting time for the patient in a day. These hospitals should review their policies to consider adapting them to accommodate patients and their loved ones more effectively.

B. Most of the Hospitals that Improved Their Policies During the Survey Year Participated in the IPFCC Training Program

The hospitals that participated in the IPFCC training program performed better as a group than those who did not. Of the ten hospitals whose scores on family presence and visitation hours improved during the period from initial screening to final screening, eight of them were hospitals that participated in the IPFCC training program and one hospital was part of a hospital network that did so. (These are marked with an asterisk). While three hospitals only improved by less than two points, the other hospitals’ improvements were substantial:

| Hospital | Point Increase | Net Change |
|---|----------------|------------|
| H+H/Bellevue* | 1.5 | 7.5 to 9 |
| Brookdale University Hospital Medical Center* | 1 | 1 to 2 |
| H+H/Coney Island* | 4 | 3 to 7 |
| H+H/Elmhurst* | 9.5 | 1.5 to 11+ |
| Flushing Hospital Medical Center* | 1 | 0 to 1 |
| Hospital for Special Surgery | 10 | 0 to 10 |
| H+H/Jacobi* | 9+ | 2 to 11+ |
| H+H/Lincoln* | 8 | 1 to 9 |
| New York-Presbyterian/Queens* | 6 | 5 to 11 |
| H+H/Woodhull* | 4 | 1 to 5 |

It should be noted that some hospital personnel who responded to calls made for the survey did not appear to be aware of the new policies and provided outdated information in response to a telephone inquiry.

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C. Blanket Restrictions Against Morning Visitation Persist at Some Hospitals

Disturbingly, six hospitals' visiting policies as posted on their websites did not provide any visiting hours whatsoever in the morning, and did not state on their website visiting pages whether any flexibility could be provided for a patient's family caregiver/care partner (*see Appendix C, Summary of Scores and Visiting Hours of NYC-based Acute Care Hospitals [100 or more beds] for specific visiting hours*).⁴¹

Such a prohibition on morning visiting hours, if followed to the letter, would mean that:

- *A patient would go the entire morning without seeing anyone from his or her personal life. This can be disorienting for some patients.*
- *The patient's loved ones would go all morning without seeing the condition of the patient for themselves.*
- *Medical personnel would miss out on important patient information that could be provided by a knowledgeable family caregiver/care partner— given that much important medical information transfer, care and decision-making occurs in the morning. And,*
- *Patients would be deprived of the advantage of having an “extra pair of ears” to listen to medical advice and maybe even take notes during this important morning period.*

None of those hospital websites provide an explanation for why they are barring morning visits. Concerns about morning “rounds” or personal care assistance does not prevent roughly 75% of the surveyed hospitals from providing morning visiting hours. Clearly, there is room for adaptability.

D. Rules on Children as Visitors Vary, with No Apparent Rhyme or Reason

Patients and their families may not be aware that visiting rules in New York City area hospitals can differ based on the age of the visitor, with the age below which such restrictions apply ranging – depending on the facility – from age 3 to as high as 14 years old.

Only 12 of the hospitals surveyed explicitly specified on their websites that children can visit. Most did so with an instruction that children under a certain age – ranging from 10 to 16 – must be supervised by an adult.

In contrast, over a third (18) of the hospitals' websites specifically prohibited, strongly discouraged or required prior authorization for visitation by children. The age thresholds below which such restrictions were found to be imposed range substantially – without explanation – from 3 to 14 years old.

This surprising range of variation in children visitation policies raises significant questions about the basis for such restrictions and the extent to which alternatives to such restrictions have been explored, given the importance of the parent-child and grandparent-child bond. While some may worry that hospitals may be upsetting for children, the American Association of Critical-Care Nurses (“AACN”) urges that concerns about children as visitors are not justified. It states:

[S]ome nurses in adult ICUs restrict children's visits based on the intuition that children will be harmed by what they see or based on a concern that they would be uncontrollable. These biases are not grounded in evidence or based on the patient's or the child's actual needs. Yet, when allowed to visit relatives in the ICU, properly prepared children have less negative behavior and fewer

41. These hospitals were Montefiore Hospital (Moses Campus); Montefiore Weiler Hospital / Jack D. Weiler Hospital (Einstein Campus); Montefiore Wakefield Hospital (Wakefield Campus); St. John's Episcopal Hospital; University Hospital SUNY Downstate and Wyckoff Heights Medical Center; Wyckoff Heights Medical Center provided such language only under a “Patient Responsibility” category, not as likely to be viewed by family caregivers.

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*emotional changes than those who did not visit. It is recommended that they be allowed to visit unless they carry contagious illnesses.*⁴²

It is notable that this professional position is taken with respect to children as visitors in ICUs, where safety issues are of great importance. Indeed, a small, anecdotal survey of 29 children (ages 4 to 17 years) visiting a relative in intensive care found that the visit “did not seem to frighten the child,” but rather generated feelings of “release and relief,” and many felt the relative “looked better” than they had imagined.⁴³ A subsequent study reported, “Children with a seriously ill/injured relative suffer. However, visiting seems to alleviate suffering.”⁴⁴

A prohibition on children as visitors can be a disturbing and unpleasant surprise. Parents, already under stress because of an illness in the family, may have limited options under these circumstances. A parent who is not able to afford or arrange for childcare apparently would not be able to be with the patient at all, resulting in unequal visitation access and quality of care for patients of low income. What is a parent supposed to do if she or he is not aware of the ban on children and arrives at the hospital with a child? And one should consider how the child feels upon learning that he or she is somehow unfit to visit.

The exclusion of teenagers from visiting hospital patients is particularly perplexing. Some teenagers hold part-time jobs, and many serve as volunteers for nonprofit organizations in their communities. In many families, teenagers play a role of significant responsibility in managing the household and caring for younger siblings. They should not be denied access to an ailing loved one, and the ailing loved one should not be denied the child’s supportive company, for no significant clinical reason.

With respect to supervision of children as visitors, the American Association of Critical-Care Nurses advocates, as part of its recommendation to allow children visitors in the ICU, a statement that, “Children are expected to remain with the adult who is supervising them.” This type of language is more specific, useful and easy to enforce than vague “must be supervised” phrasing. 🐘

42. C. Guzzetta (AACN Practice Alert), *supra*.

43. Susanne Knutsson, et al., “Children’s Experiences of Visiting a Seriously Ill/Injured Relative on an Adult Intensive Care Unit,” *J Adv Nursing* 61(2):154-62, 156 and 158 (2008).

44. Susanne Knutsson and Ingegerd Berborn, “Children’s Thoughts and Feelings Related to Visiting Critically Ill Relatives in an Adult ICU: A Qualitative Study,” *Intensive & Critical Care Nursing* 32:33-41 (Feb. 2016) (available at <http://www.sciencedirect.com/science/article/pii/S0964339715000658>, accessed July 19, 2017).

45. American Association of Critical-Care Nurses, *supra*, p. 3.

Most Hospitals in NYC Can Significantly Improve Their Websites' Usefulness to Family Caregivers /Care Partners and Visitors

The most accessible public document that a hospital produces is its website. A hospital's website can provide important information that will make it easier for family caregivers/care partners and visitors to plan a trip to the hospital. This is particularly important for people who may be traveling a significant distance to visit a patient. A well-developed hospital website can also do more than that – it can provide important guidance and warnings to help improve safety for the patient, the hospital, the family caregiver/care partner and the visitor. The benefits of accessible disclosure on the hospital's website of policies regarding family caregiver/care partner and visitor presence include:

- *Better understanding and preparation by the prospective family caregiver/care partner or visitor regarding how many people can visit at the bedside simultaneously and any special consideration regarding children as visitors;*
- *Better understanding and compliance by family caregiver/care partner and visitors regarding health and safety measures that can reduce risks for the patient, other hospital patients and staff, and the family caregiver/care partner or visitor; and,*
- *Potentially fewer telephone queries to the hospital.*

Researchers reviewed the websites for the 49 acute care hospitals that are the subject of this report to identify what information is provided to family caregivers/care partners and visitors and how easy it is to find the information prior to calling or coming to the hospital. This review found that most of the facilities' websites were significantly underutilized as information and education resources.

The quality of each website's information on visiting policy was assessed based on a series of questions, discussed below, which comprised a 10-point scale. (See Appendix B, Hospital Score Sheet Form: NYC-Area Hospital Website navigability, Helpfulness and Messaging.)

A. Availability of Visiting Hours Information on Hospital Websites

The threshold question about any hospital policy on visiting is, "Where can I find it?" Is the policy posted on the hospital website, so that both potential patients and potential visitors can understand the rules before entering the hospital? If so, is it easy to find?

The first two questions of this report's website review should have been easy "points" for the hospitals. They asked only whether the hospital's general (as opposed to maternity or intensive care) visiting hours were posted on the website, and were placed in a location that would reasonably target the attention of prospective visitors. Most websites had a clearly marked link on their main page directed toward visitors, but some websites required quite a bit of searching, and three of hospitals did not appear to have posted their visiting policies on their websites at all.

B. Statements Explicitly Encouraging Patients to Designate a Family Caregiver/Care Partner and Referring to That Individual as Part of the Healthcare Team

Two questions focused on whether the hospital's website encourages the patient to designate someone as a family caregiver/care partner and

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whether the hospital describes or discusses this person as a partner in care rather than just someone who is there to listen or to provide emotional support. Each of these questions, because of the importance of the matter as described in the Background section of this report, was awarded two points.

Providing such information on the hospital website is important not only because the patient may read it in advance of hospitalization, allowing more time to consider which family member, significant other or trusted friend would be best to play this role for the patient, but also because it notifies those who care about the patient that this designated family caregiver/care partner role exists. Someone who cares about the patient may voluntarily express to the patient a willingness to play that role.

Sixteen of the hospital websites surveyed contained clear statements encouraging the patient to designate a person or persons to serve as family caregivers/care partners and were awarded the two full points for this question. H+H/Elmhurst, for example, stated clearly on its website, “Our patients have the right to designate a family member/caregiver who may stay with the patient during their hospitalization.”⁴⁶ Another 14 hospitals had statements that strongly implied this, enough to merit the award of one point.

The number of hospitals that clearly stated that the family caregiver/care partner was a partner in care was smaller. Only 7 hospitals were awarded the full two points for this question:

H+H/Coney Island
Lenox Hill Hospital (Northwell Health)
Montefiore Hospital (Moses Campus)
Montefiore Weiler Hospital / Jack D. Weiler Hospital (Einstein Campus)
Montefiore Wakefield Hsptl (Wakefield Campus)
NY-Presbyterian/Morgan Stanley Children’s Hsptl
Staten Island U. Hsptl (Northwell Health)

An additional 15 hospitals’ websites, however, did contain language that strongly implied this role, enough to merit the award of 1 or 1.5 points.

C. Availability of Information for Family Caregivers/Care Partners and Visitors on Safety Precautions They Should Take

The subsequent three questions and bonus points focused on safety issues, asking whether the website educated family caregiver/care partner and visitors in advance that:

- *They should not come to the hospital if ill, even if all they have is a “cold”;*
- *They will need to wash or sanitize their hands before entering the patient’s room; and*
- *They should avoid bringing an item to the hospital that might trigger allergic reactions (such as latex balloons).*

A bonus point was provided if the website advised that a family caregiver/care partner or visitor may need to seek advice about bringing food into the hospital if the patient is on a special diet. A policy that provides such warnings is much more effective if a visitor can read the policy before traveling to the hospital, and if the policy provides this information on the page that a visitor is most likely to view.

Several of the websites contained this information but buried it in pages of downloadable brochures or website locations that appeared to be directed toward patients rather than their visitors. Only a half-point was provided in such instances, because a prospective visitor is less likely to click on the link or view that brochure page.

The results for these questions were far from ideal.

46. See H+H/Elmhurst’ Patients and Visitors page, <http://www.nyhealthandhospitals.org/elmhurst/visiting-hours/>, accessed July 19, 2017.

Most Hospitals...

Only one of the hospitals, New York-Presbyterian/Morgan Stanley Children's Hospital, provided a message on its website page on visiting policy urging family caregivers/care partners and visitors to wash their hands before entering the patient's room. Just 15 others included such a message somewhere else on the website or on some page of the downloadable patient guide, but not on a page that a prospective visitor is likely to view. While this warning is likely to be posted on signs within the hospital itself, providing advance warning on the website is important reinforcement given the challenges of changing people's habits to reduce hospital-acquired infections.

None of the websites reminded parents to make sure that any child visitors who come with them should wash their hands before entering the patient's room. By way of comparison, Strong Memorial Hospital in Rochester, NY had posted online a special fact sheet for visitors, entitled "Help Keep Your Loved Ones Safe From Infection," which included the useful warning not to allow children to play on the floor or bed, and to have them wash their hands as they enter and leave the room.⁴⁷

Only 8 of the hospital website pages on visiting policy – less than a quarter – warned prospective family caregivers/care partners and visitors who are ill, even if all they have is a "cold" or "sneezy" condition, not to come to the hospital. While it may seem obvious to some, many people go to work or to school with cold or flu symptoms and do not think of a cold as a significant illness. Also, people concerned about a suffering family member or friend may not be sufficiently aware that they should not come to the hospital if they are ill.⁴⁸

Only 10 of the website pages warned family caregivers/care partners and visitors about what items they should avoid bringing to the hospital to avoid allergic reactions or other problems. Latex balloons, for example, have been raised as a health concern.⁴⁹ The health-care worker population appears to have a higher rate of allergic sensitivity to latex than the general population.⁵⁰ Other members of the public particularly vulnerable to latex-related allergic sensitivity include people whose families have a history of allergies, children with spina bifida, people with congenital urinary tract abnormalities and people who undergo multiple surgeries or medical procedures.⁵¹

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47. Strong Memorial Hospital, "Help Keep Your Loved Ones Safe From Infection" (posted on webpage for hospital visitors (www.urmc.rochester.edu/strong-memorial/patients-families/visiting-information/hours-policies.cfm), accessed July 19, 2017).
 48. A few of these hospitals also urged that a person should not visit the hospital if they have been exposed recently to a contagious disease, whether or not symptoms have arisen. None of these, however, advised such people to consult their doctor about the risk of contagion. The CDC notes, for example, that it takes from 10 to 21 days after exposure for a person to develop chickenpox, and the person can be contagious from one to two days before the telltale rash appears. In contrast, the CDC reports that influenza symptoms generally start to appear one to four days after the virus enters the body, and most adults can be contagious to others beginning a day before the influenza symptoms appear. See, CDC, Factsheet: "Transmission [of Chickenpox]" (www.cdc.gov/chickenpox/about/transmission.html) and CDC, Factsheet: "How Flu Spreads" (www.cdc.gov/flu/about/disease/spread.htm).
 49. Several hospital websites contained a ban on latex balloons. Some hospitals posted directives banning flowers, but did not state whether the reason for concern was potential allergic reactions, potential bacterial contamination, or bulky clutter. Brookhaven Memorial Hospital Medical Center, for example, posted a ban on flowers from its ICUs (<http://www.brookhavenhospital.org/visiting-hours.cfm>), accessed July 19, 2017); Montefiore Medical Center facilities posted bans on flowers from oncology units and ICUs (www.montefiore.org/visitor-faq), accessed July 19, 2017); and New York-Presbyterian/Columbia University Medical Center and Weill-Cornell Medical Center posted bans on flowers from ICUs, recovery rooms, operating rooms, nurseries, labor and delivery unit, and oncology and transplant units ("Patient and Visitor Guide," <http://nyp.org/patients/index.html>), accessed July 19, 2017).
 50. The CDC notes that healthcare workers who use natural latex gloves frequently are at risk from latex allergies. It states, "While there are no overall statistics on the prevalence of latex allergy in that work force, studies do indicate that 8 to 12% of health care workers regularly exposed are sensitized, compared with 1 to 6% of the general population." CDC, "Latex Allergy" (www.cdc.gov/healthcommunication/ToolsTemplates/EntertainmentEd/Tips/LatexAllergy.html). Some hospital websites suggest using synthetic, metalized balloons known as Mylar balloons.
 51. Mayo Clinic, "Latex Allergy: Risk Factors" (www.mayoclinic.com/health/latex-allergy/DS00621/DSECTION=risk-factors), accessed July 19, 2017).

Most Hospitals...

Notably, none of the hospital websites examined posted a suggestion that family caregiver and visitors avoid wearing perfume in the hospital. The Massachusetts Nursing Association has developed a model for a “fragrance free” policy and advocates for its adoption.⁵² The concern is that some fragrances contain chemicals that can present a problem for people with multiple chemical sensitivity or can exacerbate asthma, other lung conditions, rhinitis or headaches, including migraines. A study measuring histamine release from exposure to perfume in a hospital setting found an association between perfume exposure and inflammatory conditions of the skin and airways in patients.⁵³ This is a matter that hospitals should evaluate for their policies.

Only 3 hospital websites provided guidance regarding bringing food or beverages to a patient who is in a general medical/surgical unit. This information is important because hospital patients sometimes need to be on a special diet because of their condition or the medications that they are taking. Each of these hospitals was awarded a bonus point.

D. The Substantial Room for Improvement in Website Communication Scores

Every hospital should have been able to achieve a website communication score of at least “3,” yet 11 of the hospitals did not. Simply posting visiting hours – with no other guidance or information for family caregivers/care partners and visitors – in a location on the website targeted toward prospective family caregivers/care partners and visitors in a reasonably helpful format, could give a hospital a score of “2,” yet three hospitals received a zero score.

No hospital received a perfect “10” score for the quality of their website information for visitors. The highest score, achieved by New York-Presbyterian/Morgan Stanley Children’s Hospital, was a “9.” H+H/Bellevue (which recently revised its website), Lenox Hill Hospital (Northwell) and Staten Island Hospital (Northwell Health) had the third highest score of 8 points.

Although the IPFCC training program did not focus on safety communications for visitors, it did address communication regarding the designation and role of the family caregiver/care partner. H+H/Bellevue’s score improved by 3 points, and 7 other hospitals’ scores improved somewhat – by 1, 2 or 2.5 points. 7 of these 8 hospitals (marked with an asterisk), including H+H/Bellevue, participated in the IPFCC training program or, in one hospital’s case, were part of a hospital network that did so.

All the improvements related to the designation or role of the family caregiver/care partner, or the patient’s right to choose who can be at bedside (whether as family caregiver/care partner or visitor):

- H+H/Bellevue**
- H+H/Jacobi**
- Brookdale University Hsptl Medical Center**
- H+H/Lincoln**
- H+H/Elmhurst**
- New York-Presbyterian/Queens**
- Hospital for Special Surgery*
- H+H/Woodhull**

The fact that hospitals achieved improvements in website messaging regarding family caregiver/care partner issues, while other areas of inquiry regarding website messaging that were not covered by the training did not improve, suggests that IPFCC’s training program had a positive effect. 🐾

52. See the website of the Massachusetts Nursing Association (www.massnurses.org/health-and-safety/articles/chemical-exposures/p/openItem/1346#model, accessed July 19, 2017).

53. Eberling, J., et al., “Increased Release of Histamine in Patients with Respiratory Symptoms Related to Perfume,” *Clinical & Experimental Allergy* 37: 1676-80 (2007).

54. Brookdale Hospital Medical Center, NY Presbyterian/Queens and Woodhull Medical & Mental Health Center improved regarding the patient’s right to choose visitors; the others improved regarding the designation or role of the family caregiver.

Good News: The Policies Of All Surveyed Hospitals Comply With The Patient's Legal Right To Choose Care Partners

A. The Federal Rule That Required an End to Hospital “Immediate Family Only” Visiting Policies Nationwide

In 2010, The New York Times profiled a woman named Lisa Pond, who had suffered a fatal brain aneurysm and had been hospitalized at Jackson Memorial in Miami, Florida. The New York Times explained that Janice Langbehn, her life-partner for 18 years and parent of their four adopted children, who also had power of attorney, was denied the right to be at the bedside because the hospital did not consider her to be “family.” Over a period of eight hours, Ms. Langbehn was only allowed a five-minute visit with Ms. Pond in the hospital's trauma area while a priest administered last rites. Later she was let in, but Ms. Pond was unconscious and died the next morning.⁵⁵ The story garnered the attention of President Obama, who issued a Presidential Memorandum on April 15, 2010, instructing his health secretary to produce new rules to allow patients the right to choose their hospital visitors,⁵⁶ noting this would also allow a patient with no spouse or child to have the support and comfort of a good friend.⁵⁷

In response to the April 15, 2010 Presidential Memorandum, the U.S. Department of Health and Human Services’ Centers for Medicare & Medicaid Services (CMS), issued new rules on November 10, 2010 requiring any hospital that cares for Medicare or Medicaid patients to es-

tablish a written policy giving patients control over who may be present at their bedside. The rules became effective on January 18, 2011. Under these rules, such hospitals must:

- *Establish their visiting policies and procedures in writing;*
- *State in writing the reasons for any clinically necessary or reasonable restriction or limitation on visitation rights and,*
- *Inform each patient of the visitation rights and, in particular, the right of the patient to receive visitors that he or she approves, and to deny persons visitation access.*⁵⁸

The regulation establishes the patient’s right to designate visitors. It states that any hospital that receives Medicaid or Medicare must:

- *Inform each patient (or support person, where appropriate) of the right – subject to his or her consent – to receive the visitors whom he or she designates, including, but not limited to, a spouse, a domestic partner (including a same-sex domestic partner), another family member, or a friend, and his or her right to withdraw or deny such consent at any time.*⁵⁹

And, in addition, such hospitals must “[ensure] that all visitors enjoy full and equal visitation privileges consistent with patient preferences.”⁶⁰

55. Tara Parker-Pope, “Kept from a Dying Partner’s Bedside,” New York Times (May 19, 2009).

56. President Barack Obama, “Presidential memorandum – Hospital Visitation: memorandum for the Secretary of Health and Human Services” (April 15, 2010) (<https://obamawhitehouse.archives.gov/the-press-office/presidential-memorandum-hospital-visitation>, accessed July 19, 2017).

57. Sheryl Gay Stolberg, “Obama Widens Medical Rights for Gay partners,” New York Times (Apr. 15, 2010).

58. 42 CFR Parts 482 and 485; new rules issued in 75 FR 70831 (Nov. 19, 2010).

59. 42 CFR Part 482.13(h)(2); see also Part 485.635(f)(2).

60. 42 CFR Part 482.13(h)(4); see also Part 485.635(f)(4).

Good News...

New York State had already taken significant steps in this direction before the federal rule was issued. Public Health Law § 2805-q, which took effect on June 1, 2010, states, “[no] domestic partner shall be denied any rights of visitation of his or her domestic partner when such rights are accorded to spouses and next-of-kin at any hospital, nursing home or health care facility.” The New York State Department of Health regulation that sets out the “Patient’s Bill of Rights” – which is required to be provided to every hospital patient⁶¹ – also states that the patient has the right, consistent with law, to “[authorize] those family members and other adults who will be given priority to visit consistent with your ability to receive visitors.”

The federal regulation, however, requires that the policy be in writing, and that reasons be provided for any restrictions.

Having the choice to designate someone other than a family member, domestic partner or “significant other” is particularly important for elderly people. Recent demographic statistics show that fully a third of all older Americans live alone.⁶² Moreover, the National Council on Aging reports that 17% to 19% of New York State's seniors live in social or geographic isolation, without the immediate support from a spouse or family member.⁶³ The message about their right to have a support person of their own choosing should be consistent and very clear.

B. Results of Review: All Surveyed Hospital Websites Are Now Consistent with the Regulations

An examination of the 49 hospital websites targeted by this report reveals that all of them are

consistent with the federal and New York State rules regarding the patient's right to choose and prioritize visitors. When Patient & Family and NYPIRG last conducted a survey on right-to-choose language in 2013, six hospitals in New York City had language that conflicted with these regulations, such as outdated “immediate family only” language. Now none of them have conflicting language.

Even better, 70% (34) of the hospital websites take the responsible step of affirmatively and clearly explaining this important right to patients (compared with only 10 hospital websites doing so in 2013 in the New York City area).

This is a substantial improvement, and may well be due at least in part to the New York State Department of Health’s efforts. After release of the 2013 report by Patient & Family and NYPIRG on this topic, the Department had pledged that it would work to bring all hospitals into compliance.⁶⁴

Conclusion

Several hospitals in New York City have made significant strides in reforming their policies on family caregiver/care partner presence and general visitation, but many others still have a long way to go toward achieving policies that meet patients’ needs and preferences. Providing an intensive training program with follow-up coaching calls successfully facilitated change in several hospitals. Recommendations as set out in the “Summary of Findings and Recommendations” of this report, if implemented, can reasonably be expected to enhance patients’ experiences in hospitals, the quality of care, and the smoothness of transitions from hospital to home. 🏠

61. 10 NYCRR §405.7 (effective date Dec. 22, 2010), promulgated pursuant to Public Health Law § 2805-q.

62. E. Klinenberg, S. Torres and E. Portacolone, “Aging Alone in America” (a briefing paper prepared for the Council on Contemporary Families for Older Americans Month, May 2012) (https://contemporaryfamilies.org/wp-content/uploads/2013/10/2012_Briefing_Klinenberg_Aging-alone-in-america.pdf, accessed July 20, 2017); Maggie Fox, “Report Shows More Older Americans Living Alone,” *National Journal* (May 1, 2012), Maria T. Carney, et al., “Elder Orphans Hiding in Plain Sight: A Growing Vulnerable Population,” *Current Geront & Geriatric Res* (2016) (<https://www.hindawi.com/journals/cggr/2016/4723250/>, accessed July 27, 2017).

63. National Council on Aging, *Crossing New Frontiers: Benefits Access Among Isolated Seniors* (May 2011), p. 7.

64. Letter from Ruth Leslie, Director, NYS Department of Health Division of Hospitals and Diagnostic and Treatment Centers to Suzanne Mattei, Executive Director, New Yorkers for Patient & Family Empowerment, Sept. 17, 2013.

Appendix A:

NYC-Area Hospital Policies on Family* Presence & Visiting Policy for General (Medical/Surgical) Units & ICU/CCU**

| Question/Parameter | Score (1 or 0) |
|--|----------------|
| For Medical/Surgical Units | |
| Does the website-posted policy disclose that the hospital provides two hours or more of general visiting time in the morning? | |
| Does the website-posted policy disclose that the hospital provides four hours or more of general visiting time in the morning? | |
| Does the website-posted policy disclose that the hospital may provide flexibility in visiting hours or in hours of bedside presence for a patient's designated family caregiver or other care partner/support person? | |
| Does the website-posted policy disclose that the hospital will accommodate the 24-hour presence of a patient's designated family caregiver or other care partner/support person? (Award 2 points) | |
| For ICU/CCU | |
| Does the website-posted ICU/CCU policy disclose that the hospital will accommodate the presence of a patient's designated family caregiver or other care partner/support person for periods longer than two hours? | |
| Does the website-posted ICU/CCU policy disclose that the hospital will accommodate the presence of a patient's designated family caregiver or other care partner/support person for 6 hours or more per day? | |
| Does the website-posted ICU/CCU policy disclose that the hospital will accommodate the presence of a patient's designated family caregiver or other care partner/support person for 10 hours or more per day? | |
| Does the website-posted ICU/CCU policy disclose that the hospital will accommodate 24-hour presence for a patient's designated family caregiver or other care partner/support person? (Award 2 points) | |
| Bonus: Does the website-posted policy allow children as visitors, without a prior notice requirement, in both general medical/surgical and ICU? (note: a + sign is awarded if website specifically states that children may visit; requiring supervision is not deemed discouragement) | |
| Total Score: | |

*The term "family" is defined herein to include the key support persons and loved ones in the patient's life, as determined by the patient.

**If the hospital has more than one ICU/CCU, the scoresheet will reflect the policy for the surgical ICU/CCU.

Appendix B:

NYC-Area Hospital Website Navigability, Helpfulness and Messaging*(Regarding Family** Caregiver/Care Partner Presence and Visiting)

| Question/Parameter | Score (1 or 0 unless marked for 2 points) |
|--|---|
| Does the hospital post its policy on family caregiver/care partner presence and general visiting hours on its website? | |
| Can a person find this policy on or through a link with a title that would reasonably be expected to lead to information for family caregivers/care partners or visitors (such as “Visitors” or “Patients & Visitors” or “Guide for Patients & Families” – or even “Patient Information,” rather than less obvious links such as “About” or “Admissions Information”)? | |
| Does the website-posted policy state clearly that the patient has the right to choose who can be present at bedside (in a visiting or supportive role)? | |
| Does the website-posted policy encourage patients to designate the people they want the hospital to treat as their family caregivers/care partners (sometimes called “support persons” or “primary support persons”)? (Award 2 points) | |
| Does the website-posted policy refer to the patient’s designated family caregivers/ care partners as part of the healthcare team or as care partners, rather than as “visitors”? (Award 2 points) | |
| Does the website-posted policy take the opportunity to educate the public that people who come to the hospital must sanitize or wash their hands before entering the patient's room? | |
| Does the website-posted policy take the opportunity to notify the public that one should not to come to the hospital if one is ill or even has a cold? | |
| Does the website-posted policy take the opportunity to educate the public on what gift items people should avoid bringing, to avoid allergic reactions or other problems, including latex balloons? | |
| Bonus: Does the website-posted policy notify the public that a patient may have dietary restrictions that could affect whether certain food or beverages may be brought in (rather than simply forbid such activity)? | |
| Total Score: | |

*A half-point is given if the website provides infection, allergy or diet precautions only for the ICU.

**The term “family” is defined herein to include the key support persons and loved ones in the patient’s life, as determined by the patient.

Appendix C:

SUMMARY OF SCORES & VISITING HOURS OF NYC-BASED ACUTE CARE HOSPITALS (100 or more beds)

| Scores | Specific Hours | | | | General visiting hours schedule for med/surgical units | | | | | | | | | |
|--|----------------------|-----------------------------|-------------------|--------------------------|--|-----------------------|------------|------------|-------------|-------------|---------------------------|----------|------------------|----------------------------|
| | Prior Website Scores | Prior Visiting Hours Scores | New Website Score | New Visiting Hours Score | Gen'l Visiting Hours/Policy | Starts 7AM or Earlier | Starts 8AM | Starts 9AM | Starts 10AM | Starts 11AM | No AM Hours (Starts Noon) | Ends 8PM | Ends 8:30 or 9PM | Ends After 9PM or is 24/hr |
| H+H/BELLEVUE | 5 | 7.5 | 8 | 9 | 9AM -9PM | | | ● | | | | | ● | |
| BRONX-LEBANON HOSPITAL CENTER - CONCOURSE DIVISION | 0 | 0 | 0 | 0 | 11AM -9PM | | | | | ● | | | ● | |
| BROOKDALE UNIVERSITY HOSPITAL MEDICAL CENTER | 2.5 | 1 | 5 | 2 | 11AM -8PM | | | | | ● | | ● | | |
| THE BROOKLYN HOSPITAL CENTER (DOWNTOWN CAMPUS) | 2 | 8+ | 2 | 8+ | 24/7 | ●+ | | | | | | | | ●+ |
| H+H/ CONEY ISLAND | 7.5 | 3 | 7.5 | 7 | 9AM -9PM | | | ● | | | | | ● | |
| H+H/ ELMHURST | 5.5 | 1.5 | 7.5 | 11+ | 24/7 | ●+ | | | | | | | | ●+ |
| FLUSHING HOSPITAL MEDICAL CENTER | 2 | 0 | 2 | 1 | 9AM -9PM | | | ● | | | | | ● | |
| LONG ISLAND JEWISH FOREST HILLS HSPTL (NORTHWELL HEALTH) | 7 | 9+ | 7 | 9+ | 24/7 | ●+ | | | | | | | | ●+ |
| H+H/HARLEM | 4.5 | 9+ | 4.5 | 9+ | 24/7 | ●+ | | | | | | | | ●+ |
| HOSPITAL FOR SPECIAL SURGERY | 3.5 | 0 | 6 | 10 | 24/7 | ●+ | | | | | | | | ●+ |
| INTERFAITH MEDICAL CENTER | 3 | 0 | 3 | 0 | 11AM -8PM | | | | | ● | | ● | | |
| H+H/JACOBI | 4 | 2 | 6 | 11+ | 24/7 | ●+ | | | | | | | | ●+ |
| JAMAICA HOSPITAL MEDICAL CENTER | 2.5 | 7 | 2.5 | 7 | 9AM -8PM | | | ● | | | | ● | | |
| H+H/ KING | 6.5 | 4.5+ | 7.5 | 4.5+ | 11AM -8PM | | | | | ● | | ● | | |
| KINGSBROOK JEWISH MEDICAL CENTER | 5.5 | 7 | 5.5 | 7 | 10AM -9PM | | | | ● | | | | ● | |
| LENOX HILL HOSPITAL (NORTHWELL) | 8 | 9+ | 8 | 9+ | 24/7 | ●+ | | | | | | | | ●+ |
| H+H/LINCOLN | 3 | 1 | 5.5 | 9 | 10-8PM, 15 min/hr from 9PM -8AM | | | | ●+ | | | ●+ | | |
| MAIMONIDES MEDICAL CENTER | 3 | 2 | 3 | 2 | 11AM -9:30PM | | | | | ● | | | | ● |
| MEMORIAL SLOAN KETTERING MEMORIAL HOSPITAL | 5.5 | 7+ | 5.5 | 7+ | 6AM -10PM | ● | | | | | | | | ● |

Appendix C (Continued):

SUMMARY OF SCORES & VISITING HOURS OF NYC-BASED ACUTE CARE HOSPITALS (100 or more beds)

| Scores | Specific Hours | | | | General visiting hours schedule for med/surgical units | | | | | | | | | |
|---|----------------------|-----------------------------|-------------------|--------------------------|--|-----------------------|------------|------------|-------------|-------------|---------------------------|----------|------------------|----------------------------|
| | Prior Website Scores | Prior Visiting Hours Scores | New Website Score | New Visiting Hours Score | Gen'l Visiting Hours/Policy | Starts 7AM or Earlier | Starts 8AM | Starts 9AM | Starts 10AM | Starts 11AM | No AM Hours (Starts Noon) | Ends 8PM | Ends 8:30 or 9PM | Ends After 9PM or is 24/hr |
| H+H/METROPOLITAN | 5.5 | 10 | 5.5 | 10+ | 24/7 | ●+ | | | | | | | | ●+ |
| MONTEFIORE HOSPITAL (MOSES CAMPUS) | 7.5 | 1 | 7.5 | 1 | NOON-8:30PM | | | | | | ● | | ● | |
| MONTEFIORE WEILER HOSPITAL / JACK D WEILER HOSPITAL (EINSTEIN CAMPUS) | 7.5 | 1 | 7.5 | 1 | NOON-8:30PM | | | | | | ● | | ● | |
| MONTEFIORE WAKEFIELD HOSPITAL (WAKEFIELD CAMPUS) | 7.5 | 1 | 7.5 | 1 | NOON-8:30PM | | | | | | ● | | ● | |
| MOUNT SINAI BETH ISRAEL MEDICAL CTR. (1ST AVE & 16TH) | 4 | 2 | 4 | 2 | 11AM-8PM | | | | | ● | | ● | | |
| MOUNT SINAI BROOKLYN (WAS BETH ISRAEL MED CTR. KINGS HWY) | 4 | 9+ | 4 | 9+ | 11AM-8PM | | | | | ● | | ● | | |
| MOUNT SINAI HOSPITAL | 0 | 0 | 0 | 0 | 11AM-9PM | | | | | ● | | | ● | |
| MOUNT SINAI QUEENS | 3 | 5 | 3 | 5 | 9AM-9PM | | | ● | | | | | ● | |
| MOUNT SINAI ST. LUKE'S | 5 | 3 | 5 | 3 | 9AM-9PM | | | ● | | | | | ● | |
| MOUNT SINAI WEST (WAS MOUNT SINAI ROOSEVELT) | 5 | 3 | 5 | 3 | 9AM-9PM | | | ● | | | | | ● | |
| NEW YORK COMMUNITY HSPTL OF BROOKLYN | 2 | 1 | 2 | 1 | 11AM-8PM | | | | | ● | | ● | | |
| NEW YORK PRESBYTERIAN/BROOKLYN METHODIST HOSPITAL | 2.5 | 7 | 2.5 | 7 | 9AM-8PM | | | ● | | | | ● | | |
| NEW YORK PRESBYTERIAN/ALLEN HOSPITAL | 7 | 10 | 7 | 11 | 24/7 | ●+ | | | | | | | | ●+ |
| NEW YORK PRESBYTERIAN/COLUMBIA UNIVERSITY MEDICAL CENTER | 7 | 10 | 7 | 11 | 24/7 | ●+ | | | | | | | | ●+ |
| NEW YORK PRESBYTERIAN/LOWER MANHATTAN HOSPITAL (FORMERLY NY DOWNTOWN HOSPITAL) | 6.5 | 10 | 6.5 | 11 | 24/7 | ●+ | | | | | | | | ●+ |
| NEW YORK PRESBYTERIAN/MORGAN STANLEY CHILDREN'S HOSPITAL | 9 | 11+ | 9 | 11+ | 24/7 | ●+ | | | | | | | | ●+ |

Appendix C (Continued):

SUMMARY OF SCORES & VISITING HOURS OF NYC-BASED ACUTE CARE HOSPITALS (100 or more beds)

| Scores | Specific Hours | | | | | General visiting hours schedule for med/surgical units | | | | | | | | |
|---|----------------------|-----------------------------|-------------------|--------------------------|-----------------------------|--|------------|------------|-------------|-------------|---------------------------|----------|------------------|----------------------------|
| | Prior Website Scores | Prior Visiting Hours Scores | New Website Score | New Visiting Hours Score | Gen'l Visiting Hours/Policy | Starts 7AM or Earlier | Starts 8AM | Starts 9AM | Starts 10AM | Starts 11AM | No AM Hours (Starts Noon) | Ends 8PM | Ends 8:30 or 9PM | Ends After 9PM or is 24/hr |
| Hospitals in bold participated in or benefitted from the IPFCC training program | | | | | | | | | | | | | | |
| NEW YORK PRESBYTERIAN/QUEENS | 2 | 5 | 4 | 11 | 24/7 | ●+ | | | | | | | | ●+ |
| NEW YORK PRESBYTERIAN/WEILL CORNELL MEDICAL CENTER | 7 | 10 | 7 | 11 | 24/7 | ●+ | | | | | | | | ●+ |
| H+H/NORTH CENTRAL BRONX | 3 | 11 | 3 | 11 | 24/7 | ●+ | | | | | | | | ●+ |
| NYU LANGONE ORTHOPEDIC HOSPITAL (FORMERLY HOSPITAL FOR JOINT DISEASES) | 7 | 10.5+ | 7 | 10.5+ | 24/7 | ●+ | | | | | | | | ●+ |
| NYU LANGONE'S TISCH HOSPITAL | 7 | 11+ | 7 | 11+ | 24/7 | ●+ | | | | | | | | ●+ |
| NYU LANGONE HOSPITAL - BROOKLYN (FORMERLY LUTHERAN MEDICAL CENTER) * | 6 | 6 | 2.5 | 6 | 7AM -9PM | ● | | | | | | | ● | |
| H+H/QUEENS | 3 | 10 | 3 | 10 | 24/7 | ●+ | | | | | | | | ●+ |
| RICHMOND UNIVERSITY MEDICAL CENTER (AFFILIATED W/ MOUNT SINAI) | 5 | 6 | 5 | 6 | 24/7 | ●+ | | | | | | | | ●+ |
| ST. BARNABAS HOSPITAL/SBH HEALTH SYSTEM | 2.5 | 2 | 2.5 | 2 | 11AM -8PM | | | | | ● | | ● | | |
| ST. JOHN'S EPISCOPAL HOSPITAL AT SOUTH SHORE | 2.5 | 2 | 2.5 | 2 | NOON -8PM | | | | | | ● | ● | | |
| STATEN ISLAND UNIVERSITY HOSPITAL (NORTHWELL HEALTH) | 8 | 11+ | 8 | 11+ | 24/7 | ●+ | | | | | | | | ●+ |
| UNIVERSITY HOSPITAL SUNY DOWNSTATE | 0 | 2 | 0 | 2 | NOON -8PM | | | | | | ● | ● | | |
| H+H/WOODHULL | 2 | 1 | 3 | 5 | 9AM -9PM | | | ● | | | | | ● | |
| WYCKOFF HEIGHTS MEDICAL CENTER | 5 | 3 | 4 | 3 | NOON -8PM | | | | | | ● | ● | | |

*After the survey period, the policy for this hospital was made consistent with that of NYU Langone's Tisch hospital's 24/7 general visiting hours policy.

Appendix D: Scoring Guidance Notes

POLICIES ON FAMILY PRESENCE & VISITING

ICU or similar unit to be scored:

If the hospital has more than one ICU/CCU, the scoresheet will reflect the policy for the surgical ICU/CCU. If the hospital does not list an ICU but lists a Step-Down Unit (SDU), score the SDU.

Statements possibly implying 24-hour visitation:

If the policy specifically states that 24-hour or overnight presence is allowed, give 2 points; if it offers a cot, add a plus sign (+).

If the policy uses the somewhat vague phrase that a family caregiver/care partner or visitors can be present “throughout the course of the stay,” give 1 point for questions 1-3, but only 1 point rather than 2 for question 4 regarding 24-hour presence. (Note: Including The Joint Commission’s long list of recommendations which includes advice that patients ask a trusted person to stay with them “even overnight,” if attributed to the Commission but not directly to the hospital, is not a clear, express statement of hospital policy to allow it.)

If the website language, taken together, is stronger than “throughout the stay,” such as statements regarding “open visiting hours” and “there are no set visiting times” and “the patient decides who visits and when,” and the 24/7 policy is backed up on the phone, give 2 points.

If the hospital clearly states that it allows 24/7 visiting but then “recommends” shorter hours involving less morning hours than stated in questions 1 (2 hrs.) or 2 (4 hrs.) -- and in response to a phone call the hospital personnel only gives the shorter hours -- .5 point will be given for the corresponding question regarding morning hours, as more casual visitors are likely to believe they must use the shorter hours. Full credit, however, will be given for question 4 re-

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garding 24-hour presence, as family caregivers/care partners are more likely to realize that the 24/7 option includes them.

If the hospital website obliquely says that it only allows flexibility under “special circumstances,” give a .5 point.

Statements regarding presence in the ICU:

If the hospital’s visiting policy implies that its 24/7 policy applies to the ICU and a call confirms it, but the website does not explicitly state that 24-hour presence is allowed in the ICU, provide 1 point for each of the ICU hours questions, but provide only 1 point rather than 2 for question #8 regarding whether the hospital will accommodate 24-hour presence, because overnight stays require planning and the information should be very clear for that purpose.

If the ICU states affirmatively that patients have a “right” to have a family caregiver/care partner present in the ICU “throughout the course of the stay,” but the policy also states that “visits” are limited to 15 minutes at a time, give only .5 point.

If the hospital’s visiting hours page regarding the ICU obliquely states that “only immediate family members or other persons with a close relationship may visit” give a .5 point.

Final bonus point regarding children:

Give 1 bonus point if the hospital policy allows children as visitors. Add a plus sign (+) if the website-posted policy explicitly states that children can visit.

Give only a .5 bonus point if the policy allows children in medical/surgical units but does ban children in the ICU, or if the policy states only that children “can visit most units.”

If information in a downloadable Patient Guide is out of date but up-to-date information is posted directly on the website, base the award of a bonus point on the website language.

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WEBSITE COMMUNICATIONS: NAVIGABILITY, HELPFULNESS AND MESSAGING

Website navigability:

If the viewer must click a link entitled “patient care” that doesn’t explicitly state that the visiting policy can be found there, give only .5 point.

Family caregiver as partner in care:

Where a statement on the potential role of family caregiver/care partner is included but it is limited to family and does not explain that the patient decides who fills this role and that it could be filled by someone other than a family member, give only 1 point.

If the website-posted policy implies that the patient’s support person may have a role in care by stating, for example, that they should observe and ask questions to help them provide better post-discharge care, but presents it as an instruction relationship than a partnership, give only 1 point rather than 2.

Add a plus sign (+) where the statement on the role of family caregivers/care partners is particularly clear.

Instructions for visitors regarding handwashing, illness or gift items:

If such instructions are buried in a brochure not next to visiting hours, give .5 point, but give the full 1 point if it is near or in the visiting hours section.

If the stated policy on the website conflicts with that in the downloadable patient guide, use the website, as visitors are more likely to view that than the patient guide before coming to the hospital.

For the policy on illness or cold, give only a .5 point if it does not specifically mention a cold, cough or runny nose (many people don’t think of a cold as an illness and will go to work or to other places without thinking about it). Give a .5 point if the policy only applies to children visiting but does not reference adults.

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For the policy on gift items, give only a .5 point if the website only states that people should consult with unit staff “before bringing any items for patients onto units.” This is not enough to trigger awareness that certain items could trigger allergic reactions. Information should be very clear for that purpose.

For the ICU, if “throughout the course of the stay” language is used but the policy also contains restrictions, such as 15 minute visit restrictions, give only a half point.

If the hospital’s visiting hour page regarding the ICU obliquely states that “only immediate family members or other persons with a close relationship may visit” give a .5 point.

Final bonus point regarding children:

Give 1 point if the hospital policy allows children as visitors. Add a plus sign (+) if the website-posted policy explicitly states that children can visit.

Give only a .5 point if the policy allows children in medical/surgical units but does ban children in the ICU, or if the policy states only that children “can visit most units.” ❏

Appendix E:

HOSPITALS THAT PARTICIPATED IN IPFCC TRAINING (MARCH 2016)

Public hospitals (NYC Health + Hospitals):

H+H/Bellevue
H+H/Coney Island
H+H/Elmhurst
H+H/Harlem
H+H/Jacobi
H+H/Kings County
H+H/Lincoln
H+H/North Central Bronx
H+H/Woodhull

NYC Health + Hospitals facilities participating through central management and follow-up activities:

H+H/Metropolitan
H+H/Queens

Private hospitals:

Brookdale University Hospital Medical Center
Jamaica Hospital Medical Center
NY-Presbyterian/Morgan Stanley Children's Hsptl.
NY-Presbyterian/Columbia University Medical Ctr.
NY-Presbyterian/Lower Manhattan Hospital
NY-Presbyterian/Weill Cornell Medical Center
NYU Langone Med. Ctr. Hassenfeld Children's Hsptl.
NYU Lutheran Medical Center

New York-Presbyterian facilities participating through central management and follow-up activities:

New York-Presbyterian/Queens

Appendix F:

REASONS TO MAINTAIN THE PRESENCE OF A FAMILY CAREGIVER/CARE PARTNER DURING PROVISION OF URGENT CARE OR RESUSCITATION EFFORTS

While the concern has been raised that family caregiver/care partner presence, especially during invasive procedures or cardiopulmonary resuscitation, could distract the healthcare provider and result in possible harm, significant research over the past two decades indicates otherwise, and an awareness of the benefits of such family presence has been increasing.

A study of nine years' experience at a hospital emergency department in allowing family presence during cardiopulmonary resuscitation countered the assumption that such presence would be harmful, providing evidence that family members did not interfere with health care providers and that the policy was beneficial.⁶⁵ In 2013, a study published in the *New England Journal of Medicine* looked at the effect of allowing family to be present during CPR. It found that patients with family present during CPR suffered much less PTSD-related symptoms directly afterward than those without the option.⁶⁶ Another study of patients who had the option found that a year later, the diminished anxiety and PTSD persisted.⁶⁷ In 2017, a cross sectional study published in the *American Journal of Critical Care* concluded overwhelmingly that it is in the best interest of the patient to have the option of having a support person present during resuscitation.⁶⁸

Concerns about family caregiver/care partner presence during urgent care in the ICU, such as how to manage crowding while urgent actions are taken and fear of delays caused by responding to questions from the support person⁶⁹ can be addressed. An infectious disease specialist reports that one hospital gained more success with its ICU policy on family caregiver/care partner presence after coupling it with an extensive communication program for family and staff.⁷⁰ Similarly, the National Consensus Conference on Family Presence During Pediatric Cardiopulmonary Resuscitation and Procedures recommends including education in "family presence" in all core curricula and orientation for health care providers and developing policies and procedures for such presence that include family member definition, preparation of the family, how to handle disagreements, and provision of support for staff.⁷¹ 🐘

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