SICK, SCARED & SEPARATED FROM LOVED ONES

Fourth Edition: A Pathway to Improvement in New York

NEW YORK PUBLIC INTEREST RESEARCH GROUP
NEW YORKERS FOR PATIENT & FAMILY EMPOWERMENT
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Established in 1976, the New York Public Interest Research Group Fund (NYPIRG) is a nonpartisan, not-for-profit organization whose mission is to educate the public on policy issues and advance reforms, while training New Yorkers to be advocates. Governmental accountability, political reform, consumer protection, environmental preservation, health care and public health, higher education, and mass transit are among NYPIRG's principal areas of concern.

New Yorkers for Patient and 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 health care 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 key supporters in the patient's life, as determined by the patient.

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. For further information, please visit IPFCC's website: www.ipfcc.org.

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Executive Summary

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Executive Summary

Leading advocates for patient- and family-centered care have urged that a culture change needs to take place regarding how hospital policy-makers, clinicians, 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.

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.[1] In 2014, the Institute for Patient- and Family-Centered Care (IPFCC) launched an international campaign, ***Better Together**: Partnering with Families*. A 2015 profile of the campaign focusing on several hospitals found that family presence increased patient satisfaction and reduced hospital-acquired infections.[2] Important policy changes at the Federal and State levels in recent years has encouraged hospitals to change policies and practice about family caregivers and care partners. For example, New York State passed the Caregiver Advise, Record and Enable (CARE) Act in 2015 and it went into effect in April 2016. With the new law, now passed by 40 states, hospitals are to record the name of patients' designated family caregivers and provide these persons with information to prepare for transitions from hospitals to home and community care.[3]

A study of almost 1,500 hospitals conducted in 2013-2014 by the Health Research & Educational Trust (HRET) found that hospitals that allowed unrestricted access to patients by family and care partners across all units had HCAHPS[4] scores that were 3.0 points higher.[5] A 2016 study of the transition from a more restrictive to less restrictive policy on family caregiver/care partner presence in the Intensive Care Unit (ICU) found that patient satisfaction increased while nurses did not report any increase in interference with medical care.[6] For further information about the developments in this work, please see the "Background" section on page 28.

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 support persons whom the hospital should consider to be partners in care for the patient.[7] 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.

New Yorkers for Patient & Family Empowerment ("Patient & Family") and the New York Public Interest Research Group ("NYPIRG") have three times before examined hospital policies on family and visitor presence and found them wanting. The most recent previous report, published in January 2018, and now this one, included the Institute for Patient- and Family-Centered Care (IPFCC), which provided training programs to help hospitals reexamine and improve their practices. Our analysis in this report examines whether this intervention helped change hospitals' policies and practices.

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[1] 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).

[2] 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).

[3] https://www.aarp.org/content/dam/aarp/ppi/2019/03/the-care-act-implementation-progress-and-promise.pdf

[4] HCAHPS stands for Hospital Consumer Assessment of Healthcare Providers and Systems. It is a patient satisfaction survey required by the Centers for Medicare and Medicaid Services for all hospitals in the United States.

[5] Health Research & Educational Trust. (2015). *Patient and family engagement and patient satisfaction: Results of a national survey*. Chicago, IL: Health Research and Educational Trust.

[6] Diane Chapman, *et al*., "Satisfaction with Elimination of all Visitation Restrictions in a Mixed-Profile Intensive Care Unit," *Am J Critical Care* 25(1):46-50 (Jan. 2016) (https://www.aacn.org/docs/cemedia/A1625013.pdf, accessed July 16, 2017).

[7] 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.

This report presents findings and recommendations based on a review of visiting policies, family presence and participation policies, and website communications for forty hospitals in New York State. The report identifies improvements in the policies of many of the hospitals that participated in the IPFCC ***Better Together*** **Learning Community** program. Participation in the IPFCC program also appears to have made a difference with respect to better online communication about the designation or role of family caregivers/care partners, the right to choose visitors, and providing information helpful to prospective family caregivers/care partners and visitors. However, the report still found some shortcomings in transparency and clarity of messaging for patients, family caregivers/care partners and visitors in nearly all hospital websites surveyed.

Summary of Findings

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SUMMARY OF FINDINGS

Finding: Some Hospitals in New York State Provide Many More Hours of Visiting than Others and Better Accommodate the Presence of Family Caregivers/Care Partners.

NYPIRG and Patient & Family surveyed each hospital's website twice – in fall of 2018 and then in summer of 2019 – 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 being present with the hospital patient. Each evaluation also included the potential of one bonus point.

- In the final survey of 40 hospitals' policies, 21 (53%) received a high score of 8 or better, and 17 of these received a "perfect" 10 (Some also received an additional bonus point for their policy on children as visitors.) based on their visitation or family presence policies.

- In the survey, more than two thirds (27) of the hospitals were found to provide 12 or more hours of visiting time per day, with 17 of these hospitals now offering 24-hour "open" visitation for general medical/surgical units. Two others stated or implied that they offered 24-hour "flexibility," including particularly for the patient's family caregiver/care partner.

- Some hospitals, in contrast, had posted policies that significantly restricted patients' access to family and other trusted people. Nearly a fifth of the hospitals (7) scored only between 0 and 3. (See Appendix C, Summary of Scores and Visiting Hours of Hospitals.)

- One hospital (see Appendix C) received a zero score, meaning the hospital offered no more than a single hour of general visitation in the morning, did not mention flexibility or accommodation for a family caregiver/care partner, and provided less than two hours at a time of family caregiver/care partner presence in the ICU.

This survey also revealed divergent rules for child visitors:

- Twenty-three hospitals' websites (58%) explicitly communicated that children could visit. Twenty of those hospitals included instructions that children could visit so long as a supervising adult was with the child.

- A quarter of the hospitals' websites (10) 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.

- One hospital allowed child visitors with a supervising adult in the Medical/Surgical unit, but restricted visits to children age 13 and above in the Intensive Care Unit.

- Six hospitals did not provide any guidance on visitors who are children.

- Inexplicably, the age below which a child's visit was restricted ranged from ages 10 to 18, 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.

Finding: Hospitals that Participated in the IPFCC *Better Together* Learning Community Improved Their Caregiver Access Policies During the Survey Year

The hospitals that participated in the IPFCC ***Better Together*** **Learning Community** program tended to perform better, as a group, with respect to improved policy scores than those who did not. During the survey period, 16 out of 40 hospitals' policy scores improved. Of those, hospitals which did not participate in the IPFCC program saw an average increase in scores of 2.01 points (an 18% score increase). The hospitals that participated in the IPFCC **Learning Community** saw an average increase in scores of 4 points (an 36% score increase), with the top three increases in scores belonging to hospitals that participated in the IPFCC program.

> In an unusual development, two Rockland County hospitals included in this project were impacted by a measles outbreak which began in October 2018. Responding to the outbreak, actions by the county's Department of Health precipitated temporary visitor policy changes at those hospitals (Nyack Hospital and Good Samaritan Hospital of Rockland County). The scoring included in this report reflects these hospitals' temporary policies, as the outbreak occurred during our survey period. Since the conclusion of our survey period, the Rockland County Department of Health has declared an end to the outbreak, and, subsequently, the visitor policies have been restored.

Finding: Some Hospitals in New York State Provide Better Website Communication for Patients, Family Caregivers/Care Partners and Well-Wishing Visitors

A hospital's website is its most public interface; it is an important tool for communicating with prospective patients, family caregivers/care partners, and visitors. More and more, people today rely on websites for information. The hospital's website also creates powerful first impressions for prospective employees, conveying messages about whether or not the organization views patients and families as part of the care team as well as the importance of partnerships with patients and families.

This report evaluated the navigability, helpfulness and messaging of the hospital websites surveyed on a 10-point scale. Each evaluation was also eligible for one bonus point. Based on this measure, many of the hospital websites are not realizing their potential:

- In the final survey of 40 hospitals' policies, 13 (32.5%) received a high score of 8 or better. Another 9 hospitals received a score of 7; therefore, a total of 22 hospitals (55%) were rated 7 or above.
- However, none received a perfect score, based on the visitation or family presence policies posted on their websites, the prime source of information for members of the public.
- On a positive note, 18 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 three hospitals had statements that strongly implied this.
- Fourteen hospitals clearly declared the family caregiver/care partner as a partner in care. An additional 10 hospitals included "partner in care" language although it was in a difficult to find location or was exclusively used for family members.
- Nine of the hospital websites received a very low website score of only "3" or below, with one of these receiving a score of zero (See Appendix C.).
- Many 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. Few hospital websites warned family members and prospective visitors having a cold, the flu, or a cough not to come to the hospital. Even fewer websites included instructions about gifts to avoid bringing to prevent allergic reactions or other problems.

- Sixteen of the hospitals examined took the opportunity on its visiting-policy webpage to inform family caregivers, care partners, and visitors of the need to wash their hands. Eight other hospitals included a statement about hand-washing on a page of the website or patient guide less likely to be viewed by family caregivers, care partners, and visitors or included these instructions only for sick or child visitors. Sixteen of the hospital website-posted family presence or visiting policies contained no instruction whatsoever.

- Eleven of the hospital websites warned prospective family caregivers, care partners, and visitors having a cold, the flu, or a cough not to come to the hospital. Six other hospitals included instructions not to visit while sick only for children, in locations less likely to be viewed by family caregivers, care partners, and visitors, or included only vague directions about visiting while sick. Twenty-three hospital website-posted family presence or visiting policies contained no instruction.

- Only seven hospital websites included instructions about gifts to avoid bringing to prevent allergic reactions or other problems, including latex balloons. Four other hospitals included these instructions in locations less likely to be viewed by a visitor.

Finding: Hospitals that Participated in the IPFCC *Better Together* Learning Community Improved Their Scores for Website Navigability, Helpfulness, and Messaging

The hospitals that participated in the IPFCC ***Better Together*** **Learning Community** tended to perform better, as a group, with respect to improved website navigability, helpfulness, and messaging scores than those who did not. During the survey period, 28 out of 40 hospitals' website navigability scores improved. Of those, hospitals which did not participate in the IPFCC **Learning Community** saw an average increase in scores of 1.2 points (an 11% score increase). The hospitals that had participated in the IPFCC program saw an average increase in scores of 2.7 points (an 25% score increase), with the top five largest increases in scores belonging to hospitals that participated in the IPFCC **Learning Community**.

Finding: Improvement Was Facilitated When Addressed Across a Health System and with Leadership Support

- Fifteen hospitals from Northwell Health participated in the IPFCC ***Better Together*** **Learning Community**. (Only fourteen hospitals were surveyed because one hospital, Long Island Jewish Forest Hills, became a participant *after* the initial fall 2018 survey. Although the hospital participated fully, its final scores could not be included in this report.)

- Twelve of the Northwell hospitals started with "perfect" scores for policy. However, changes were needed in website messaging. Over a 10-month period, almost all the hospitals significantly improved their web scores. Northwell hospitals were also able to move beyond the policy and website parameters of the survey to integrate family caregiver/care partner concepts in employee position descriptions and performance management. (For further information about how Northwell hospitals more broadly changed both policy and practice, review a profile at: https://www.ipfcc.org/bestpractices/better-together-featured-system.html or read the article in the January/February 2019 issue, in press, of the Journal of Clinical Outcomes Management.)

- This improvement was due in large part to Northwell's system-wide approach to participation in the ***Better Together*** **Learning Community** and to strong leadership support.

- This same finding related to leadership support and a system-wide approach was described in the third report, "Sick, Scared & Separated from Loved Ones," published in 2018, about the participation of hospitals from the NYC Health + Hospitals system.

Recommendations

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Recommendation #1 (24-Hour Presence): If a hospital supports and encourages a 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 remove restrictions on family caregiver/care partner presence.

Recommendation #3 (Designation of Family Caregiver/Care Partner): 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/Care Partner): The hospital's website-posted policy should clarify that a patient-designated family caregiver/care partner 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 (Safety Information): The hospital's website-posted policy should:

- Explicitly instruct that anyone with a cold, rash, fever, influenza, cough, or other communicable disease should not visit the hospital. Many people do not think of a cold as an illness. This policy should not just apply to child visitors.
- 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.

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 and changed or deleted. (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 hospital 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 or revising policies and website communication 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 support services, patients and their family caregivers/care partners, and health consumer advocates. Many hospitals now have formal structures called Patient and Family Advisory Councils. Recent research has shown that these councils can be very effective in influencing hospital leadership, strategies, and operations to reflect the priorities, needs, and preferences of patients and families.[8]

Recommendation #9 (Website Development): Key hospital leaders who are knowledgeable about the quality, safety, and experience of care, along with patient and family advisors, should work with communications and marketing teams or departments on revising the messaging and navigability of websites.

Recommendation #10 (Best Practice Guidance/Expertise and Resources): In developing or revising policies and website communication to support family caregiver/care partner presence and participation, hospitals should be aware of and utilize recognized expertise and resources in the field that define best practice in this area.

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[8] Institute for Patient- and Family-Centered Care (2018). *Strategically advancing patient and family advisory councils in New York State Hospitals*. Bethesda, MD: Institute for Patient- and Family-Centered Care.

Overall and Detailed Findings

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SICK, SCARED & SEPARATED FROM LOVED ONES
OVERALL FINDINGS – POLICIES ON CAREGIVER ACCESS

Overall Finding: Several New York State hospitals currently operate with policies that are very flexible about visiting and that recognize the importance of the presence of family caregivers/care partners. Using a 10-point scale that we have used to rank hospitals' visitation policies in our previous reports, 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/care partners, and length of visiting periods allowed in the ICU (See Appendix A, *Hospital Score Sheet Form: Hospital Policies on Family Caregiver Presence and Visiting*). A bonus point was awarded if the hospital accommodates children as visitors.

Of the hospitals surveyed, 17 received a "perfect 10" (or more, if awarded a bonus point). The hospitals below received the highest scores.

Why this matters: Research evidence has identified substantial benefits that occur when hospitals maximize patients' access to their personal support system of loved ones and friends.[9] Hospitals' policies should reflect the evidence and offer the broadest access to patients by loved ones and family caregivers/care partners.

Hospitals That Scored Highest

Clifton Springs Hospital
Glen Cove Hospital
Huntington Hospital
Lenox Hill Hospital
Long Island Jewish–Valley Stream Hospital
Long Island Jewish Medical Center
Maria Fareri Children's Hospital
Newark Wayne Community Hospital
North Shore University Hospital
Northern Westchester Hospital
Peconic Bay Medical Center
Phelps Memorial Hospital
Plainview Hospital
Southside Hospital
St. Joseph Hospital
Staten Island University Hospital

Hospitals That Ranked a Close Second

Champlain Valley Physician's Hospital
Cohen Children's Medical Center

Finding: Hospitals that Participated in the IPFCC *Better Together* Learning Community Program Improved Their Caregiver Access Policies During the Survey Year

The hospitals that participated in the IPFCC program tended to perform better, as a group, with respect to improved policy scores than those who did not. During the survey period, 16 out of 40 hospitals' policy scores improved. (See chart below). Of those, hospitals that did not participate in the IPFCC program saw an average increase in scores of 2.1 points (an 18% score increase). The hospitals that had participated in the IPFCC program saw an average increase in scores of 4 points (an 36% score increase), with the top three biggest increases in scores belonging to hospitals that participated in the IPFCC program.

Note: Several hospitals, especially those in the Northwell Health system, received "perfect" scores in the Fall 2018 review. Therefore, increases were not possible.

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[9] 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)

Why this matters: It is important for hospitals to follow best practices and to work with experts to adapt them to the particular circumstances of the individual institution. The results of our survey show that when presented with that information, hospitals do make changes to improve visitations' policies.

Hospital (Bold face IPFCC participants)	2019 Score	Change in Score From 2018
Clifton Springs Hospital	**10**	**10**
Elizabethtown Community Hospital	**8**	**8**
Phelps Memorial Hospital	**11+**	**6.5**
Westchester Medical Center	8+	6
Sisters of Charity Hospital	6	3
St. Luke's Cornwall	5	3
Zucker Hillside Hospital	**2**[10]	**2**
Unity Hospital	**4**	**2**
St. Catherine of Siena Medical Center	6+	2
Catskill Regional Medical Center	**5**	**2**
Maria Fareri Children's Hospital	10+	1
Memorial Sloan Kettering	6	1
Orange Regional Medical Center	**5.5**	**0.5**
St. Joseph Hospital	10.5	0.5
Long Island Community Hospital[11]	2.5	0.5

[10] Zucker Hillside Hospital, a psychiatric hospital, does not have an ICU/CCU, and therefore could not be awarded points for the second half of the *Caregiver Policies* survey questions. For the *Caregiver Policies* survey, the maximum score Zucker Hillside Hospital was eligible for was 6 points, as opposed to 11 for other hospitals.

[11] Formerly named Brookhaven Memorial Hospital.

DETAILED FINDINGS – POLICIES ON CAREGIVER ACCESS

Finding for Question #1: Does the website-posted policy disclose that the hospital provides two hours or more of general visiting time in the morning?

Hospitals That Provide 2 Hours of Visiting in the AM

Catskill Regional Medical Center
Champlain Valley Physician's Hospital
Clifton Springs Hospital
Cohen Children's Medical Center
Elizabethtown Community Hospital
Faxton/St. Luke's/St. Elizabeth
Glen Cove Hospital
Good Samaritan Hospital (Rockland County)
Huntington Hospital
Lenox Hill Hospital
Long Island Community Hospital
Long Island Jewish–Valley Stream Hospital
Long Island Jewish Medical Center
Memorial Sloan Kettering
Newark Wayne Community Hospital
North Shore University Hospital
Northern Westchester Hospital
Nyack Hospital
NYP Brooklyn Methodist Hospital
Orange Regional Medical Center
Peconic Bay Medical Center
Phelps Memorial Hospital
Plainview Hospital
Southside Hospital
St. Joseph Hospital
St. Luke's Cornwall
Staten Island University Hospital
United Memorial Medical Center
White Plains Hospital

Hospitals Where the Policy Is Vague[12]

Albany Medical Center
Maria Fareri Children's Hospital
Westchester Medical Center

Hospitals That Do Not Provide 2 Hours of Visiting in the AM

Alice Hyde Medical Center
Buffalo General
Good Samaritan Hospital (Suffolk County)
Montefiore Moses
Sisters of Charity
St. Catherine of Siena Medical Center
Unity Hospital
Zucker Hillside Hospital

[12] These hospitals' general visiting hours do not provide for two hours of morning visitation, but does explicitly allow for "a support person to be present with the patient during the course of stay." Therefore, they were awarded half-points. In addition, Maria Fareri Children's Hospital's website lists visiting hours of 11:00am – 9:00 pm, whereas the Patient Guide's Visitors information listed hours of 9:00 am – 9:00 pm, see: http://www.westchestermedicalcenter.com/Uploads/Public/Documents/MFCH/MFCHPatientGuide2018.pdf.

Finding for Question #2: Does the website-posted policy disclose that the hospital provides four hours or more of general visiting time in the morning?

Hospitals That Provide 4 Hours of Visiting in the AM

Champlain Valley Physician's Hospital
Clifton Springs Hospital
Cohen Children's Medical Center
Elizabethtown Community Hospital
Faxton/St. Luke's/St. Elizabeth
Glen Cove Hospital
Huntington Hospital
Lenox Hill Hospital
Long Island Jewish–Valley Stream Hospital
Long Island Jewish Medical Center
Memorial Sloan Kettering
Newark Wayne Community Hospital
North Shore University Hospital
Northern Westchester Hospital
Nyack Hospital
Peconic Bay Medical Center
Phelps Memorial Hospital
Plainview Hospital
Southside Hospital
St. Joseph Hospital
St. Luke's Cornwall
Staten Island University Hospital

Hospitals Where The Policy Is Vague[13]

Albany Medical Center
Maria Fareri Children's Hospital
Westchester Medical Center
Catskill Regional Medical Center[14]

Hospitals That Do Not Provide 4 Hours of Visiting in the AM

Alice Hyde Medical Center
Buffalo General Medical Center
Good Samaritan Hospital (Rockland County)
Good Samaritan Hospital (Suffolk County)
Long Island Community Hospital
Montefiore Moses
NYP Brooklyn Methodist Hospital
Orange Regional Medical Center
Sisters of Charity Hospital
St. Catherine of Siena Medical Center
United Memorial Medical Center
Unity Hospital
White Plains Hospital
Zucker Hillside Hospital

[13] These hospitals' general visiting hours do not provide for four hours of morning visitation, but do explicitly allow for "a support person to be present with the patient during the course of stay." Therefore, they were awarded half-points.

[14] Catskill Regional Medical Center's website lists both 9:00 am – 9:00 pm and 8:00 am – 9:00pm visitor hours, so was awarded half points.

Finding for Question #3: 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?

Hospitals That Provide Flexibility in Visiting Hours of Hours of Bedside Presence

Albany Medical Center
Catskill Regional Medical Center
Champlain Valley Physician's Hospital
Clifton Springs Hospital
Cohen Children's Medical Center
Elizabethtown Community Hospital
Faxton/St. Luke's/St. Elizabeth
Glen Cove Hospital
Good Samaritan Hospital (Suffolk County)
Huntington Hospital
Lenox Hill Hospital
Long Island Community Hospital
Long Island Jewish–Valley Stream Hospital
Long Island Jewish Medical Center
Maria Fareri Children's Hospital
Memorial Sloan Kettering
Montefiore Moses
Newark Wayne Community Hospital
North Shore University Hospital
Northern Westchester Hospital
NYP Brooklyn Methodist Hospital
Peconic Bay Medical Center
Phelps Memorial Hospital
Plainview Hospital
Sisters of Charity Hospital
Southside Hospital
St. Catherine of Siena Medical Center
St. Joseph Hospital
Staten Island University Hospital
Unity Hospital
Westchester Medical Center
Zucker Hillside Hospital

Hospitals That Do Not Provide Flexibility

Alice Hyde Medical Center
Buffalo General Medical Center
Good Samaritan Hospital (Rockland County)
Nyack Hospital
Orange Regional Medical Center
St. Luke's Cornwall
United Memorial Medical Center
White Plains Hospital

Finding for Question #4: 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?

Hospitals That Accommodate 24-hour Presence by Family Caregiver or Care Partner

Catskill Regional Medical Center
Cohen Children's Medical Center
Glen Cove Hospital
Huntington Hospital
Lenox Hill Hospital
Long Island Jewish – Valley Stream Hospital
Long Island Jewish Medical Center
Newark Wayne Community Hospital
North Shore University Hospital
Northern Westchester Hospital
Peconic Bay Medical Center
Phelps Memorial Hospital
Plainview Hospital
Southside Hospital
St. Joseph Hospital
Staten Island University Hospital

Hospitals That Are Vague about 24-hour Presence of Family Caregiver or Care Partner[15]

Albany Medical Center
Champlain Valley Physician's Hospital
Clifton Springs Hospital
Elizabethtown Community Hospital
Long Island Community Hospital
Maria Fareri Children's Hospital
Sisters of Charity Hospital
St. Catherine of Siena Medical Center
Westchester Medical Center
Zucker Hillside Hospital

Hospitals That Do Not Accommodate 24-hour Presence of Family Caregiver or Care Partner

Alice Hyde Medical Center
Buffalo General Medical Center
Faxton/St. Luke's/St. Elizabeth
Good Samaritan Hospital (Rockland County)
Good Samaritan Hospital (Suffolk County)
Memorial Sloan Kettering
Montefiore Moses
Nyack Hospital
NYP Brooklyn Methodist Hospital
Orange Regional Medical Center
St. Luke's Cornwall
United Memorial Medical Center
Unity Hospital
White Plains Hospital

Finding for Question #5: Does the website-posted ICU/CCU policy disclose that the hospital will accommodate the presence of a patient's designated family or other care partner/support person for periods longer than 2 hours?

Hospitals That Accommodate Family Caregiver or Care Partner Presence for Periods Longer than 2 Hours in ICU/CCU

Albany Medical Center
Alice Hyde Medical Center
Champlain Valley Physician's Hospital
Clifton Springs Hospital
Cohen Children's Medical Center
Elizabethtown Community Hospital
Faxton/St. Luke's/St. Elizabeth
Glen Cove Hospital
Good Samaritan Hospital (Rockland County)
Good Samaritan Hospital (Suffolk County)
Huntington Hospital
Lenox Hill Hospital
Long Island Jewish–Valley Stream Hospital
Long Island Jewish Medical Center
Maria Fareri Children's Hospital
Memorial Sloan Kettering
Montefiore Moses
Newark Wayne Community Hospital
North Shore University Hospital
Northern Westchester Hospital
Nyack Hospital
NYP Brooklyn Methodist Hospital
Orange Regional Medical Center
Peconic Bay Medical Center
Phelps Memorial Hospital
Plainview Hospital
Sisters of Charity Hospital
Southside Hospital
St. Catherine of Siena Medical Center
St. Joseph Hospital
St. Luke's Cornwall
Staten Island University Hospital
United Memorial Medical Center
Unity Hospital
Westchester Medical Center
White Plains Hospital

[15] These hospitals have policies which may imply that they will accommodate the 24-hour presence of a patient's designated family caregiver/care partner, but suggest shorter hours, require special permission, or only mention family in their policy.

Hospitals That Do Not Accommodate Family Caregiver or Care Partner Presence for Periods Longer than 2 Hours in ICU/CCU

Buffalo General Medical Center
Catskill Regional Medical Center
Long Island Community Hospital

Finding for Question #6: Does the website-posted ICU/CCU policy disclose that the hospital will accommodate the presence of a patient's designated family or other care partner/support person for periods of 6 hours or more per day?

Hospitals That Accommodate Family Caregiver or Care Partner Presence for Periods of 6 Hours or Longer in ICU/CCU

Albany Medical Center
Alice Hyde Medical Center
Champlain Valley Physician's Hospital
Clifton Springs Hospital
Cohen Children's Medical Center
Elizabethtown Community Hospital
Faxton/St. Luke's/St. Elizabeth
Glen Cove Hospital
Good Samaritan Hospital (Rockland County)
Good Samaritan Hospital (Suffolk County)
Huntington Hospital
Lenox Hill Hospital
Long Island Jewish – Valley Stream Hospital
Long Island Jewish Medical Center
Maria Fareri Children's Hospital
Memorial Sloan Kettering
Newark Wayne Community Hospital
North Shore University Hospital
Northern Westchester Hospital
Nyack Hospital
NYP Brooklyn Methodist Hospital
Orange Regional Medical Center
Peconic Bay Medical Center
Phelps Memorial Hospital
Plainview Hospital
Sisters of Charity Hospital
Southside Hospital
St. Catherine of Siena Medical Center
St. Joseph Hospital
St. Luke's Cornwall
Staten Island University Hospital
United Memorial Medical Center
Unity Hospital
Westchester Medical Center
White Plains Hospital

Hospitals That Do Not Accommodate Family Caregiver or Care Partner Presence for Periods of 6 Hours or Longer in ICU/CCU

Buffalo General Medical Center
Catskill Regional Medical Center
Long Island Community Hospital
Montefiore Moses

Finding for Question #7: Does the website-posted ICU/CCU policy disclose that the hospital will accommodate the presence of a patient's designated family or other care partner/support person for periods of 10 hours or more per day?

Hospitals That Accommodate Family Caregiver or Care Partner Presence for Periods of 10 Hours or Longer in ICU/CCU

Champlain Valley Physician's Hospital
Clifton Springs Hospital
Cohen Children's Medical Center
Elizabethtown Community Hospital
Faxton/St. Luke's/St. Elizabeth
Glen Cove Hospital
Huntington Hospital
Lenox Hill Hospital
Long Island Jewish – Valley Stream Hospital
Long Island Jewish Medical Center
Maria Fareri Children's Hospital
Newark Wayne Community Hospital
North Shore University Hospital
Northern Westchester Hospital
Nyack Hospital
NYP Brooklyn Methodist Hospital
Orange Regional Medical Center
Peconic Bay Medical Center
Phelps Memorial Hospital
Plainview Hospital
Sisters of Charity Hospital
Southside Hospital
St. Catherine of Siena Medical Center
St. Joseph Hospital
St. Luke's Cornwall
Staten Island University Hospital
United Memorial Medical Center
Westchester Medical Center

Hospitals That Do Not Accommodate Family Caregiver or Care Partner Presence for Periods of 10 Hours or Longer in ICU/CCU

Albany Medical Center
Alice Hyde Medical Center
Buffalo General Medical Center
Catskill Regional Medical Center
Good Samaritan Hospital (Rockland County)
Good Samaritan Hospital (Suffolk County)
Long Island Community Hospital
Memorial Sloan Kettering
Montefiore Moses
Unity Hospital
White Plains Hospital

Finding for Question #8: Does the website-posted ICU/CCU policy disclose that the hospital will accommodate the 24-hour presence of a patient's designated family or other care partner/support person?

Hospitals That Accommodate 24-hour Presence of Family Caregiver or Care Partner in ICU/CCU

Clifton Springs Hospital
Glen Cove Hospital
Lenox Hill Hospital
Long Island Jewish – Valley Stream Hospital
Maria Fareri Children's Hospital
Newark Wayne Community Hospital
North Shore University Hospital
Northern Westchester Hospital
NYP Brooklyn Methodist Hospital
Peconic Bay Medical Center
Phelps Memorial Hospital
Plainview Hospital
Southside Hospital
St. Joseph Hospital
Staten Island University Hospital

Hospitals Where the Policy Is Vague[16]

Albany Medical Center
Catskill Regional Medical Center
Champlain Valley Physician's Hospital
Cohen Children's Medical Center[17]
Elizabethtown Community Hospital
Huntington Hospital
Long Island Jewish Medical Center
Orange Regional Medical Center
Sisters of Charity Hospital
Westchester Medical Center

Hospitals That Do Not Accommodate 24-hour Presence of Family Caregiver or Care Partner in ICU/CCU

Alice Hyde Medical Center
Buffalo General Medical Center
Faxton/St. Luke's/St. Elizabeth
Good Samaritan Hospital (Rockland County)
Good Samaritan Hospital (Suffolk County)
Long Island Community Hospital
Memorial Sloan Kettering
Montefiore Moses
Nyack Hospital
St. Catherine of Siena Medical Center
St. Luke's Cornwall
United Memorial Medical Center
Unity Hospital
White Plains Hospital

Finding for Caregiver Policy Bonus Question: Does the website-posted policy allow children as visitors, without a prior notice requirement, in both medical/surgical and ICU?[18]

Hospitals That Allow Children as Visitors

Albany Medical Center
Champlain Valley Physician's Hospital
Clifton Springs Hospital
Glen Cove Hospital
Huntington Hospital
Lenox Hill Hospital
Long Island Jewish – Valley Stream Hospital
Long Island Jewish Medical Center
Maria Fareri Children's Hospital
Memorial Sloan Kettering
Newark Wayne Community Hospital
North Shore University Hospital
Northern Westchester Hospital
Orange Regional Medical Center[19]
Peconic Bay Medical Center
Phelps Memorial Hospital
Plainview Hospital
Southside Hospital
St. Catherine of Siena Medical Center
St. Joseph Hospital[20]
Staten Island University Hospital
Unity Hospital
Westchester Medical Center

Hospitals That Provide No Guidance about Children as Visitors

Alice Hyde Medical Center
Catskill Regional Medical Center
Elizabethtown Community Hospital
Long Island Community Hospital
St. Luke's Cornwall
White Plains Hospital

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[16] These hospitals ICU/CCU policies may not have been clearly listed on the visitors page or patients handbook and needed a follow-up call to confirm. Visitors may not take that step; therefore, these hospitals were awarded partial points for this question.

[17] Cohen Children's Medical Center's 24-hour ICU visitor's policy is only listed for family, and therefore was awarded partial points for this question.

[18] A + sign is awarded if website specifically states that children may visit; requiring supervision is not deemed discouragement.

[19] Orange Regional Medical Center's policy on children as visitors is that they are allowed as visitors in the medical/surgical unit, but restricted (13 years +) in the ICU. Therefore, they were awarded with a half-point.

[20] St. Joseph Hospital's policy was found in an obscure part of its website that prospective visitors may not find. Therefore, they were awarded with a half-point.

Hospitals That Do Not Allow Children as Visitors or Require Prior Permission

Buffalo General Medical Center
Cohen Children's Medical Center
Faxton/St. Luke's/St. Elizabeth
Good Samaritan Hospital (Rockland County)[21]
Good Samaritan Hospital (Suffolk County)
Montefiore Moses
Nyack Hospital[22]
NYP Brooklyn Methodist Hospital
Sisters of Charity Hospital
United Memorial Medical Center
Zucker Hillside Hospital

[21] Rockland County Good Samaritan Hospital's child visitors policy was temporarily changed and made more restrictive due to the measles outbreak.

[22] Nyack Hospital's children visitors policy was temporarily changed and made more restrictive due to the measles outbreak.

SICK, SCARED & SEPARATED FROM LOVED ONES
OVERALL FINDINGS – WEBSITE NAVIGABILITY

For most patients, 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 highlight the important role of family caregivers/care partners for hospitalized patients. It can also 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 include:

- Awareness on the part of family members and other care partners of the role they play when a loved one is hospitalized;
- Better understanding and preparation of 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 and its staff and clinicians.

Overall Finding: In this project, researchers reviewed the websites for the 40 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 many of the facilities' websites could be significantly revised in order to be a useful resource for patients and their family caregivers/care partners. 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.*)

Why this matters: Research evidence has identified substantial benefits that occur when hospitals maximize patients' access to their personal support system of loved ones and friends.[23] Hospitals' policies should reflect the evidence and offer the broadest access to patients by family caregivers/care partners, while also effectively communicating that policy.

Hospitals That Scored Highest

Cohen Children's Medical Center
Glen Cove Hospital
Huntington Hospital
Lenox Hill Hospital
Long Island Jewish – Valley Stream Hospital
Long Island Jewish Medical Center
Maria Fareri Children's Hospital
Memorial Sloan Kettering
North Shore University Hospital
Plainview Hospital
Southside Hospital
St. Catherine of Siena Medical Center
Staten Island University Hospital

Hospital That Ranked a Close Second

Clifton Springs Hospital
Montefiore Moses
Newark Wayne Community Hospital
Northern Westchester Hospital
Sisters of Charity Hospital
Westchester Medical Center
Zucker Hillside Hospital

[23] 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).

Finding: Hospitals that Participated in the IPFCC *Better Together* Learning Community Improved Their Scores for Website Navigability, Helpfulness, and Messaging

The hospitals that participated in the IPFCC ***Better Together*** **Learning Community** tended to perform better, as a group, with respect to improved website navigability scores, than those who did not. During the survey period, 28 out of 40 hospitals' website navigability scores improved. Of those, hospitals which did not participate in the IPFCC program saw an average increase in scores of 1.2 points (an 11% score increase). The hospitals that had participated in the IPFCC **Learning Community** saw an average increase in scores of 2.7 points (an 25% score increase), with the top five biggest increases in scores belonging to hospitals that participated in the IPFCC program.

Why this matters: It is important for hospitals to follow best practices and to work with experts to adapt them to the particular circumstances of the individual institution.

Hospital (Bold face IPFCC participants)	2019 Score	Change in Score From 2018
Clifton Springs Hospital	**7**	**7**
Cohen Children's Medical Center	**8.5**	**5**
Southside Hospital	**8+**	**5**
Glen Cove Hospital	**8+**	**4.5**
Zucker Hillside Hospital	**7.5+**	**3.5**
Albany Medical Center	6	3
Plainview Hospital	**8.5+**	**3**
Long Island Jewish – Valley Stream Hospital	**8+**	**2.5**
Huntington Hospital	**8+**	**2.5**
Maria Fareri Children's Hospital	8.5	2
Lenox Hill Hospital	**9+**	**2**
Long Island Jewish Medical Center	**8+**	**2**
Unity Hospital	**5.5**	**1.5**
Memorial Sloan Kettering	8	1.5
Northern Westchester Hospital	**7**	**1.5**
North Shore University Hospital	**8+**	**1.5**
Peconic Bay Medical Center	**4**	**1.5**
Westchester Medical Center	7+	1
Sisters of Charity	7	1
Nyack Hospital	4	1
NYP Brooklyn Methodist	4.5	1
United Memorial Medical Center	**6**	**1**
Montefiore Moses	7	1
Staten Island University Hospital	**8+**	**1**
St. Luke's Cornwall	2.5	0.5
St. Catherine of Siena	9	0.5
Good Samaritan Hospital (Suffolk County)	4.5	0.5
Newark Wayne Community Hospital	**7.5**	**0.5**

Finding: Many Hospitals Surveyed Can Significantly Improve Their Websites' Helpfulness To Family Caregivers/Care Partners And Visitors

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 family caregivers, care partners, and visitors can understand the policies 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 family caregivers, care partners, and visitors. Most websites had a clearly marked link on their main page directed toward visitors, but one website required quite a bit of searching, and one hospital did not appear to have posted their visiting policies on their websites at all.

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 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 (see page 28), 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.

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 family caregivers, care partners or 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.

DETAILED FINDINGS – WEBSITE NAVIGABILITY

Finding for Question #1: Does the hospital post its policy on family caregiver/care partner presence and general visiting hours on its website?

Hospitals That Did Post Policies on Family Caregiver or Care Partner Presence and General Visiting hours on Their Websites

Albany Medical Center
Alice Hyde Medical Center
Buffalo General Medical Center
Catskill Regional Medical Center
Champlain Valley Physician's Hospital
Clifton Springs Hospital
Cohen Children's Medical Center
Faxton/St. Luke's/St. Elizabeth
Glen Cove Hospital
Good Samaritan Hospital (Rockland County)
Good Samaritan Hospital (Suffolk County)
Huntington Hospital
Lenox Hill Hospital
Long Island Community Hospital
Long Island Jewish – Valley Stream Hospital
Long Island Jewish Medical Center
Maria Fareri Children's Hospital
Memorial Sloan Kettering
Montefiore Moses
Newark Wayne Community Hospital
North Shore University Hospital
Northern Westchester Hospital
Nyack Hospital
NYP Brooklyn Methodist Hospital
Orange Regional Medical Center
Peconic Bay Medical Center
Phelps Memorial Hospital
Plainview Hospital
Sisters of Charity Hospital
Southside Hospital
St. Catherine of Siena Medical Center
St. Joseph Hospital
St. Luke's Cornwall
Staten Island University Hospital
United Memorial Medical Center
Unity Hospital
Westchester Medical Center
White Plains Hospital
Zucker Hillside Hospital

Hospitals That Did Not Post Policies on Family Caregiver or Care Partner Presence and General Visiting hours on Their Websites

Elizabethtown Community Hospital

Finding for Question #2: 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")*?

Hospital Websites Where It Was Easy to Find Information for Family Caregivers or Care Partners

Albany Medical Center
Alice Hyde Medical Center
Buffalo General Medical Center
Catskill Regional Medical Center
Champlain Valley Physician's Hospital
Clifton Springs Hospital
Cohen Children's Medical Center
Faxton/St. Luke's/St. Elizabeth
Glen Cove Hospital
Good Samaritan Hospital (Rockland County)
Good Samaritan Hospital (Suffolk County)
Huntington Hospital
Lenox Hill Hospital
Long Island Community Hospital
Long Island Jewish – Valley Stream Hospital
Long Island Jewish Medical Center
Maria Fareri Children's Hospital
Memorial Sloan Kettering
Montefiore Moses
Newark Wayne Community Hospital

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North Shore University Hospital
Northern Westchester Hospital
Nyack Hospital
NYP Brooklyn Methodist Hospital
Orange Regional Medical Center
Peconic Bay Medical Center
Phelps Memorial Hospital
Plainview Hospital
Sisters of Charity Hospital
Southside Hospital
St. Catherine of Siena Medical Center
St. Joseph Hospital
Staten Island University Hospital
United Memorial Medical Center
Unity Hospital
Westchester Medical Center
White Plains Hospital
Zucker Hillside Hospital

Hospital Websites Where It Was Too Difficult to Find Information for Family Caregivers/Care Partners

Elizabethtown Community Hospital
St. Luke's Cornwall

Finding for Question #3: 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)?

Hospitals Where the Websites Were Clear about the Patient's Right to Choose

Albany Medical Center
Alice Hyde Medical Center
Buffalo General Medical Center
Catskill Regional Medical Center
Clifton Springs Hospital
Cohen Children's Medical Center
Glen Cove Hospital
Huntington Hospital
Lenox Hill Hospital
Long Island Jewish – Valley Stream Hospital
Long Island Jewish Medical Center
Maria Fareri Children's Hospital
Memorial Sloan Kettering
Montefiore Moses
Newark Wayne Community Hospital
North Shore University Hospital
Northern Westchester Hospital
Peconic Bay Medical Center
Phelps Memorial Hospital
Plainview Hospital
Sisters of Charity Hospital
Southside Hospital
St. Catherine of Siena Medical Center
Staten Island University Hospital
Westchester Medical Center
Zucker Hillside Hospital

Hospitals Where the Websites Were Not Clear about the Patient's Right to Choose

Champlain Valley Physician's Hospital
Elizabethtown Community Hospital
Faxton/St. Luke's/St. Elizabeth
Good Samaritan Hospital (Rockland County)
Good Samaritan Hospital (Suffolk County)
Long Island Community Hospital
Nyack Hospital
NYP Brooklyn Methodist Hospital
Orange Regional Medical Center
St. Joseph Hospital
St. Luke's Cornwall
United Memorial Medical Center
Unity Hospital
White Plains Hospital

Finding for Question #4: 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")?

Hospitals That Encourage Designation of Family Caregivers/Care Partners

Glen Cove Hospital
Huntington Hospital
Lenox Hill Hospital
Long Island Jewish – Valley Stream Hospital
Long Island Jewish Medical Center
Maria Fareri Children's Hospital
Memorial Sloan Kettering
Montefiore Moses
North Shore University Hospital
Phelps Memorial Hospital
Plainview Hospital
Sisters of Charity Hospital
Southside Hospital
St. Catherine of Siena Medical Center
St. Joseph Hospital
Staten Island University Hospital
Westchester Medical Center
Zucker Hillside Hospital

Hospitals Where the Encouragement Is Ambiguous[24]

Catskill Regional Medical Center
Cohen's Children's Medical Center
Northern Westchester Hospital

Hospitals That Do Not Encourage Designation of Family Caregivers/Care Partners

Albany Medical Center
Alice Hyde Medical Center
Buffalo General Medical Center
Champlain Valley Physician's Hospital
Clifton Springs Hospital
Elizabethtown Community Hospital
Faxton/St. Luke's/St. Elizabeth
Good Samaritan Hospital (Rockland County)
Good Samaritan Hospital (Suffolk County)
White Plains Hospital
Long Island Community Hospital
Newark Wayne Community Hospital
Nyack Hospital
NYP Brooklyn Methodist Hospital
Orange Regional Medical Center
Peconic Bay Medical Center
St. Luke's Cornwall
United Memorial Medical Center
Unity Hospital

Finding for Question #5: 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"?

Hospitals That Do Designate Family Caregivers or Care Partners as Part of the Team

Albany Medical Center
Clifton Springs Hospital
Glen Cove Hospital
Huntington Hospital
Lenox Hill Hospital
Long Island Jewish – Valley Stream Hospital
Long Island Jewish Medical Center
Newark Wayne Community Hospital
North Shore University Hospital
Plainview Hospital
Sisters of Charity Hospital
Southside Hospital
Staten Island University Hospital
Zucker Hillside Hospital

[24] These hospitals' policies encouraging patients to designate a family caregiver/care partner was either difficult to find or only included family members in the policy. These hospitals received partial points for this question.

Hospitals in Which the Designation Is Ambiguous[25]

Cohen Children's Medical Center
Long Island Community Hospital
Maria Fareri Children's Hospital
Memorial Sloan Kettering
Montefiore Moses
NYP Brooklyn Methodist Hospital
Orange Regional Medical Center
Phelps Memorial Hospital
United Memorial Medical Center
Unity Hospital

Hospitals That Do Not Designate Family Caregivers or Care Partners as Part of the Team

Alice Hyde Medical Center
Buffalo General Medical Center
Catskill Regional Medical Center
Champlain Valley Physician's Hospital
Elizabethtown Community Hospital
Faxton/St. Luke's/St. Elizabeth
Good Samaritan Hospital (Rockland County)
Good Samaritan Hospital (Suffolk County)
Northern Westchester Hospital
Nyack Hospital
Peconic Bay Medical Center
St. Catherine of Siena Medical Center
St. Joseph Hospital
St. Luke's Cornwall
Westchester Medical Center
White Plains Hospital

Finding for Question #6: 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?

Hospitals That Urge Hand Washing

Glen Cove Hospital
Huntington Hospital
Lenox Hill Hospital
Long Island Jewish – Valley Stream Hospital
Long Island Jewish Medical Center
Maria Fareri Children's Hospital
North Shore University Hospital
Northern Westchester Hospital
Nyack Hospital
Plainview Hospital
Southside Hospital
St. Catherine of Siena Medical Center
Staten Island University Hospital
United Memorial Medical Center
Westchester Medical Center
White Plains Hospital

Hospitals in Which the Policy is Difficult to Find or Narrowly Applied

Catskill Regional Medical Center
Cohen Children's Medical Center
Good Samaritan Hospital (Suffolk County)
Montefiore Moses
Newark Wayne Community Hospital
NYP Brooklyn Methodist Hospital
Phelps Memorial Hospital
Unity Hospital

Hospitals That Do Not Urge Hand Washing

Albany Medical Center
Alice Hyde Medical Center
Buffalo General Medical Center
Champlain Valley Physician's Hospital
Clifton Springs Hospital
Elizabethtown Community Hospital
Faxton/St. Luke's/St. Elizabeth
Good Samaritan Hospital (Rockland County)
Long Island Community Hospital
Memorial Sloan Kettering
Orange Regional Medical Center
Peconic Bay Medical Center
Sisters of Charity Hospital
St. Joseph Hospital
St. Luke's Cornwall
Zucker Hillside Hospital

[25] These hospitals had policies about family caregiver/supports persons being a partner in care that were vague, hard to find, or only applied to family.

Finding for Question #7: 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?

Hospitals That Urge Those Who Are Sick Not to Visit

Champlain Valley Physician's Hospital
Clifton Springs Hospital
Cohen Children's Medical Center
Maria Fareri Children's Hospital
Newark Wayne Community Hospital
Northern Westchester Hospital
Nyack Hospital
St. Catherine of Siena Medical Center
United Memorial Medical Center
Unity Hospital
Westchester Medical Center

Hospitals in Which the Policy Is Ambiguous[26]

Albany Medical Center
Good Samaritan Hospital (Suffolk County)
Memorial Sloan Kettering
Montefiore Moses
NYP Brooklyn Methodist Hospital
St. Luke's Cornwall

Hospitals with No Guidance about Those Who Are Sick Coming to the Hospital

Alice Hyde Medical Center
Buffalo General Medical Center
Catskill Regional Medical Center
Elizabethtown Community Hospital
Faxton/St. Luke's/St. Elizabeth
Glen Cove Hospital
Good Samaritan Hospital (Rockland County)
Huntington Hospital
Lenox Hill Hospital
Long Island Community Hospital
Long Island Jewish – Valley Stream Hospital
Long Island Jewish Medical Center
North Shore University Hospital
Orange Regional Medical Center
Peconic Bay Medical Center
Phelps Memorial Hospital
Plainview Hospital
Sisters of Charity Hospital
Southside Hospital
St. Joseph Hospital
Staten Island University Hospital
White Plains Hospital
Zucker Hillside Hospital

Finding for Question #8: 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?

Hospitals that Urge Caution about Gift Items

Cohen Children's Medical Center
Good Samaritan Hospital (Suffolk County)
Lenox Hill Hospital
Memorial Sloan Kettering
Orange Regional Medical Center
Peconic Bay Medical Center
St. Catherine of Siena Medical Center

[26] These hospitals have sick visitor instructions in a hard to find location, have policies that are narrowly applied (for instance only for sick children), or are otherwise vague.

Hospitals In Which the Caution Is Hard to Find

Maria Fareri Children's Hospital
Northern Westchester Hospital
NYP Brooklyn Methodist Hospital
Plainview Hospital

Hospitals Without Warnings about Gift Items

Albany Medical Center
Alice Hyde Medical Center
Buffalo General Medical Center
Catskill Regional Medical Center
Champlain Valley Physician's Hospital
Clifton Springs Hospital
Elizabethtown Community Hospital
Faxton/St. Luke's/St. Elizabeth
Glen Cove Hospital
Good Samaritan Hospital (Rockland County)
Huntington Hospital
Long Island Community Hospital
Long Island Jewish – Valley Stream Hospital
Long Island Jewish Medical Center
Montefiore Moses
Newark Wayne Community Hospital
North Shore University Hospital
Nyack Hospital
Phelps Memorial Hospital
Sisters of Charity Hospital
Southside Hospital
St. Joseph Hospital
St. Luke's Cornwall
Staten Island University Hospital
United Memorial Medical Center
Unity Hospital
Westchester Medical Center
White Plains Hospital
Zucker Hillside Hospital

Finding for Website Navigation Bonus Question: 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)?

Hospital Websites that Include Notification about Dietary Restrictions

Clifton Springs Hospital
Cohen Children's Medical Center
Newark Wayne Community Hospital
St. Catherine of Siena Medical Center
St. Luke's Cornwall
United Memorial Medical Center
Unity Hospital

Hospital Websites Where Dietary Notifications Are Ambiguous[27]

Albany Medical Center
Good Samaritan Hospital (Suffolk County)
Memorial Sloan Kettering
Northern Westchester Hospital
Zucker Hillside Hospital

[27] These hospitals had dietary restriction information in a hard to find location, or had vague directions.

Hospital Websites that Do Not Include Notification about Dietary Restrictions

Alice Hyde Medical Center
Buffalo General Medical Center
Catskill Regional Medical Center
Champlain Valley Physician's Hospital
Elizabethtown Community Hospital
Faxton/St. Luke's/St. Elizabeth
Glen Cove Hospital
Good Samaritan Hospital (Rockland County)
Huntington Hospital
Lenox Hill Hospital
Long Island Community Hospital
Long Island Jewish – Valley Stream Hospital
Long Island Jewish Medical Center
Maria Fareri Children's Hospital
Montefiore Moses
North Shore University Hospital
Nyack Hospital
NYP Brooklyn Methodist Hospital
Orange Regional Medical Center
Peconic Bay Medical Center
Phelps Memorial Hospital
Plainview Hospital
Sisters of Charity Hospital
Southside Hospital
St. Joseph Hospital
Staten Island University Hospital
Westchester Medical Center
White Plains Hospital

Background

SICK, SCARED & SEPARATED FROM LOVED ONES
2019

BACKGROUND: THE BENEFITS OF POLICIES THAT MAXIMIZE THE PRESENCE OF FAMILY CAREGIVERS/CARE PARTNERS AND 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."*[28]
>
> Samuel M. Brown, MD, *The BMJ*, 2015

Leading advocates for patient- and family-centered care have urged that a culture change needs to take place regarding how hospital policy-makers, clinicians, 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.

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 support persons whom the hospital should consider to be partners in care for the patient.[29] 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, and hospital policies and practices should recognize their different roles.

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.[30]

In 2014, the Institute for Patient- and Family-Centered Care (IPFCC) launched an international campaign, ***Better Together**: Partnering with Families*. The campaign called on hospitals to eliminate restrictive "visiting" policies and to welcome families as members of the care team. A 2015 article profiling the campaign and focusing on several hospitals found that family presence increased patient satisfaction and reduced hospital-acquired infections.[31]

Research increasingly indicates that for many older patients, hospitalization for acute or critical illness is associated with reduced cognitive function.[32] 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. A study of almost 1,500 hospitals conducted in 2013-2014 by the Health

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[28] S. M. Brown, "We Still Lack Patient Centered Visitation in Intensive Care Units," *The BMJ*, *350*, h792, (2015).

[29] 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.

[30] 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).

[31] 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).

[32] 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/).

Research & Educational Trust (HRET) found that hospitals that allowed unrestricted access to patients by family and care partners across all units had HCAHPS[33] scores that were 3.0 points higher.[34] A 2016 study of the transition from a more restrictive to less restrictive policy on family caregiver/care partner presence in the Intensive Care Unit (ICU) found that patient satisfaction increased while nurses did not report any increase in interference with medical care.[35]

Important policy changes at the State and Federal levels in recent years have precipitated changes to hospital policies and practices in regard to family caregivers and care partners.

State Regulations Support Designation of a Patient-Chosen Family Caregiver/Care Partner

New York State's 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 patient[36] – 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."

Going further, New York State and 39 other states have enacted the Caregiver Advise, Record and Enable (CARE) Act.[37] 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,[38] as well as a guide to help patients and family caregivers/care partners understand the law and their role in its implementation.[39]

Federal Requirements Establish That Patients Have a Right to Family Caregiver/Care Partners of Their Choosing

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.[40]

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[33] HCAHPS stands for Hospital Consumer Assessment of Healthcare Providers and Systems. It is a patient satisfaction survey required by the Centers for Medicare and Medicaid Services for all hospitals in the United States.

[34] Health Research & Educational Trust. (2015). *Patient and family engagement and patient satisfaction: Results of a national survey*. Chicago, IL: Health Research and Educational Trust.

[35] Diane Chapman, *et al*., "Satisfaction with Elimination of all Visitation Restrictions in a Mixed-Profile Intensive Care Unit," *Am J Critical Care* 25(1):46-50 (Jan. 2016) (https://www.aacn.org/docs/cemedia/A1625013.pdf, accessed July 16, 2017).

[36] 10 NYCRR §405.7 (effective date Dec. 22, 2010), promulgated pursuant to Public Health Law § 2805-q.

[37] https://www.aarp.org/content/dam/aarp/ppi/2019/03/the-care-act-implementation-progress-and-promise.pdf

[38] 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).

[39] 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).

[40] Tara Parker-Pope, "Kept from a Dying Partner's Bedside," *New York Times* (May 19, 2009).

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,[41] noting this would also allow a patient with no spouse or child to have the support and comfort of a good friend.[42] 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 establish a written policy giving patients control over who may be present at their bedside, limited only by specific clinical considerations. 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;
- 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.[43]

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.[44]

And, in addition, such hospitals must "Ensure that all visitors enjoy full and equal visitation privileges consistent with patient preferences."[45]

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.[46] 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.[47] The message about their right to have a support person of their own choosing should be consistent and very clear.

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."[48] CMS also noted that disruptive behavior, a patient's need for rest or privacy, and other reasons for restrictions also may be considered.[49]

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[41] 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).

[42] Sheryl Gay Stolberg, "Obama Widens Medical Rights for Gay partners," *New York Times* (Apr. 15, 2010).

[43] 42 CFR Parts 482 and 485; new rules issued in 75 FR 70831 (Nov. 19, 2010).

[44] 42 CFR Part 482.13(h)(2); *see also* Part 485.635(f)(2).

[45] 42 CFR Part 482.13(h)(4); *see also* Part 485.635(f)(4).

[46] 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).

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

[48] *See* 75 F.R. 70831, 70839 (Nov. 19, 2010) and 75 FR 29479 (May 26, 2010).

[49] 75 FR 70831, 70839 (Nov. 19, 2010).

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."[50]

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."[51] 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 wherever possible.[52]

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 "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 Role of the Family Caregiver/Care Partner

The Institute for Patient- and Family-Centered Care (IPFCC) advocates that the family must be "respected as part of the care team,"[53] rather than being excluded at important stages in care and care planning. 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.[54]

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.

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[50] 75 FR 70831, 70839 (Nov. 19, 2010).

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

[52] 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).

[53] Institute for Patient- and Family-Centered Care, "Changing Hospital 'Visiting' Policies and Practices: Supporting Family Presence and Participation" (August 2010).

[54] 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).

The Joint Commission, which accredits hospitals[55] 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.[56]

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."[57] 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 coordination or inadequate information transfer, especially during transitions from one care provider to another.[58] 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.[59]

Family caregiver/care partner presence is beneficial not only in general medical/surgical units but also in the ICU.

Family caregiver/care partner presence can "foster communication, understanding and collaboration between the family and health care providers."[60] Don Berwick, a former head of the federal Centers for Medicare and Medicaid, has long recommended accommodation of family caregivers/care partners in ICUs.[61]

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[55] 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).

[56] 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).

[57] The Joint Commission, "R^3 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).

[58] *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).

[59] 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).

[60] 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).

[61] D. Berwick and M. Kotagal, *supra*.

The findings of a 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.[62] [*citations omitted*]

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*[63] 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."[64]

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.[65] 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."[66]

In contrast, unnecessary restrictions create unnecessary risks. A study comparing ICU patients' 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.[67] 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 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.[68]

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[62] Shiva Khaleghparast, *et al.*, "A Review of Visiting Policies in Intensive Care Units," *Glob J Health Sci* 8(6):267-276 (June 2016).

[63] D.M. Berwick and M. Kotagal, *supra.*

[64] 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).

[65] Diane Chapman, *et al.*, "Satisfaction with Elimination of all Visitation Restrictions in a Mixed-Profile Intensive Care Unit," *Am J Critical Care* 25(1):46-50 (Jan. 2016) (https://www.aacn.org/docs/cemedia/A1625013.pdf, accessed July 16, 2017).

[66] C. Guzetta, 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).

[67] Stefano Fumagalli, *et al.*, "Reduced Cardiocirculatory Complications with Unrestrictive Visiting Policy in an Intensive Care Unit," *Circulation*, 112:946-952 (2006).

[68] 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).

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 hospital 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.[69]

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.[70]

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, 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

The gap between written policies and implementation practices 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.

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[69] 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.

[70] 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/wol1/doi/10.1111/jgs.14873/full, accessed July 17, 2017) (a meta-analysis of several studies).

The result could be an unintended yet *de facto* disparity in patient care. Hospital administration 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 three 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.[71]

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. 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.[72]

The third report, issued by Patient & Family and NYPIRG with IPFCC in 2018, focused its survey on New York City hospitals and used the same methodology as this report. First, surveyors examined hospitals' visitation policies. Then, IPFCC used a "best practices" educational training/coaching intervention for interested hospitals. Finally, surveyors completed a second review to examine changes in hospitals' policies after the training took place. 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 or, in one hospital's case, were part of a hospital network that did so. Six of these hospitals are part of the New York City Health + Hospitals ("H+H) system.

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

[72] 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).

This Report: Family Caregiver or Care Partner Presence and Visiting Policies and the Role of the IPFCC *Better Together* Learning Community Program

The review described in this, fourth, report focused on New York State hospitals – employing the methodology used in the previous report. This report evaluates policies on family presence and visiting for general medical and surgical units and for the Intensive Care or Critical Care Unit ("ICU" or "CCU").[73]

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

The researchers conducted a preliminary survey in the fall of 2018 focusing of information posted on hospital websites regarding policies for family caregiver/care partner and visitor presence. Where visiting hours were not posted or appeared unclear,[74] a telephone call was made to the hospital's main switchboard to request the information. The results were tabulated and analyzed.

Shortly before this initial survey, 24 of the hospitals surveyed had chosen to participate in the ***Better Together*** **Learning Community** program offered by IPFCC. The hospitals were organized into two cohorts, each of which participated in six to eight group mentoring calls with IPFCC staff.

A second survey was conducted in the summer of 2019 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 NYS Hospitals* – and the performance of hospitals that participated in the IPFCC **Learning Community** were compared to those of hospitals that did not participate.

The 10-point score sheet 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 presence 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 score sheet 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.

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[73] This report does not address Maternity Unit policies.

[74] 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.

Conclusion

As the previous sections of this report detail, for 10 years, the New York Public Interest Research Group and New Yorkers for Patient and Family Empowerment have been engaged in research about family presence and general visitation policies and practice in acute care hospitals in New York State. Our reports show that, overall, the trends are positive. More hospitals are recognizing the need for hospitalized patients to have access to their family caregivers/care partners and visitors. More hospitals are effectively communicating this through their websites.

This, our fourth report, was based on the recent review of forty hospitals in the State. It confirms that a number of hospitals made significant strides in reforming their policies on and website communication about family caregiver/care partner presence and general visitation, but others still have a long way to go toward achieving policies that meet patients' needs and preferences. Providing an intensive "learning community" with coaching, based on IPFCC's ***Better Together*** **Learning Community** initiative, successfully facilitated change in a number of hospitals. Recommendations, as set out in the "Summary of Findings and Recommendations" of this report, if implemented, can enhance the experience of patients and families in hospitals, the quality and safety of care, and the smoothness of transitions from hospital to home.

APPENDIX A

Hospital Policies on Family* Caregiver/Care Partner Presence and Visiting
for General Medical/Surgical Units and ICUs/CCUs**

Question/Parameter	Score (1 or 0)
For Medical/Surgical Units	
1. Does the website-posted policy disclose that the hospital provides **two hours** or more of general visiting time in the morning?	
2. Does the website-posted policy disclose that the hospital provides **four hours** or more of general visiting time in the morning?	
3. 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/care partner (or "support person" or "primary support person")?	
4. Does the website-posted policy disclose that the hospital will accommodate the **24-hour** presence of a patient's designated family caregiver/care partner (or "support person" or "primary support person")? (*Award 2 points*)	
For ICU/CCU	
5. Does the website-posted **ICU/CCU** policy disclose that the hospital will accommodate the presence of a patient's designated family caregiver/care partner (or "support person" or "primary support person") for periods **longer than two hours**?	
6. Does the website-posted **ICU/CCU** policy disclose that the hospital will accommodate the presence of a patient's designated family caregiver/care partner (or "support person" or "primary support person") for **6 hours or more** per day?	
7. Does the website-posted **ICU/CCU** policy disclose that the hospital will accommodate the presence of a patient's designated family caregiver/care partner (or "support person" or "primary support person") for **10 hours or more** per day?	
8. Does the website-posted **ICU/CCU** policy disclose that the hospital will accommodate **24-hour** presence for a patient's designated family caregiver/care partner (or "support person or primary 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

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

Question/Parameter	Score (1 or 0 unless marked for 2 pts)
1. Does the hospital **post** its policy on family caregiver/care partner presence and general visiting hours on its website?	
2. 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")*?	
3. 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)?	
4. 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*)	
5. 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*)	
6. 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?	
7. 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**?	
8. 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 SELECTED NY HOSPITALS

Hospitals in bold participated in an IPFCC Learning Community. Cohort 1 is highlighted purple, Cohort 2 is highlighted orange.	**Prior Website Score**	**New Website Score**	**Prior Policy Score**	**New Policy Score**	**VISITING HOURS POLICY AS LISTED (Med/Surg)**
Albany Medical Center	3	6	7	7	12:00 pm - 8:30 pm, open for support persons
Alice Hyde Medical Center	3	3	2	2	11:00 am - 8:30 pm
Buffalo General Medical Center	3	3	0	0	11:00 am - 9:00 pm
Catskill Regional Medical Center	4.5	4.5	3	5	9:00 am – 9:00 pm
Champlain Valley Physician's Hospital	3	3	9.5	9.5	Open visitation until 8:30 pm
Clifton Springs Hospital	0	7	0	10	24/7
Cohen Children's Medical Center	3.5	8.5	11+	9	24/7
Elizabethtown Community Hospital	0	0	0	8[1]	24/7, not posted online
Faxton/St. Luke's/St. Elizabeth	2	2	6	6	8:00 am - 8:00 pm
Glen Cove Hospital	3.5	8+	11+	11+	24/7
Good Samaritan Hospital (Rockland County)[2]	2	2	3.5	3	24/7
Good Samaritan Hospital (Suffolk County)	4	4.5	3	3	11:00 am - 8:00 pm

[1] Elizabethtown Community Hospital's visitor policy is not listed on their website and necessitated a follow-up call.

[2] Nyack Hospital's survey results were impacted by a measles outbreak which began in October 2018. Responding to the outbreak, actions by the county's Department of Health precipitated temporary visitor policy changes. The scoring included in this report reflects these hospitals' temporary policies, as the outbreak occurred during our survey period. Since the conclusion of our survey period, the Rockland County Department of Health has declared an end to the outbreak, and, subsequently, the visitor policies have been restored.

Hospitals in bold participated in an IPFCC Learning Community. Cohort 1 is highlighted purple, Cohort 2 is highlighted orange.	**Prior Website Score**	**New Website Score**	**Prior Policy Score**	**New Policy Score**	**VISITING HOURS POLICY AS LISTED (Med/Surg)**
Huntington Hospital	5.5+	8+	11+	10+	6:00 am - 9:00 pm suggested, open for family caregiver/ care partner
Lenox Hill Hospital	7	9+	11+	11+	24/7
Long Island Community Hospital[3]	4	3	2	2.5	9:00 am - 9:00 pm
Long Island Jewish – Valley Stream Hospital	5.5+	8+	11+	11+	24/7
Long Island Jewish Medical Center	6	8+	11+	10+	24/7
Maria Fareri Children's Hospital	6.5	8.5	9	9.5+	9:00 am - 9:00 pm
Memorial Sloan Kettering	6.5	8	5	6	Open, preferred 6:00 am - 10:00 pm
Montefiore Moses	6	7	2	2	12:00 pm - 8:30 pm
Newark Wayne Community Hospital	7	7.5	11	11	24/7
North Shore University Hospital	6.5+	8+	11+	11+	24/7
Northern Westchester Hospital	5.5	7	11+	11+	24/7
Nyack Hospital[4]	3	4	5	5	8:00 am - 9:00 pm
NYP Brooklyn Methodist Hospital	3.5	4.5	7	7	9:00 am - 8:00 pm
Orange Regional Medical Center	4	4	5	5.5	9:00 am - 9:00 pm

[3] Formerly named Brookhaven Memorial Hospital.

[4] Good Samaritan Hospital of Rockland County's survey results were impacted by a measles outbreak which began in October 2018. Responding to the outbreak, actions by the county's Department of Health precipitated temporary visitor policy changes. The scoring included in this report reflects these hospitals' temporary policies, as the outbreak occurred during our survey period. Since the conclusion of our survey period, the Rockland County Department of Health has declared an end to the outbreak, and, subsequently, the visitor policies have been restored.

Hospitals in bold participated in an IPFCC Learning Community. Cohort 1 is highlighted purple, Cohort 2 is highlighted orange.	**Prior Website Score**	**New Website Score**	**Prior Policy Score**	**New Policy Score**	**VISITING HOURS POLICY AS LISTED (Med/Surg)**
Peconic Bay Medical Center	2.5	4	10+	11+	24/7
Phelps Memorial Hospital	6.5	6.5	4.5	11+	24/7
Plainview Hospital	5.5+	8.5+	11+	11+	24/7
Sisters of Charity Hospital	6	7	3	6	11:00 am - 8:00 pm
Southside Hospital	3	8+	11+	11+	24/7
St. Catherine of Siena Medical Center	8.5	9	4+	6+	11:00 am - 8:00 pm
St. Joseph Hospital	4	4	10	10.5	24/7
St. Luke's Cornwall	2	2.5	2	5	7:30 am - 9:00 pm
Staten Island University Hospital	7	8+	11+	11+	24/7
United Memorial Medical Center	5	6	4	4	9:00 am - 9:00 pm
Unity Hospital	4	5.5	2	4	11:00 am - 8:00 pm suggested
Westchester Medical Center	6	7+	2+	8+	11:00 am - 9:00 pm
White Plains Hospital	3	3	3	3	10:00 am - 9:00 pm
Zucker Hillside Hospital	4	7.5+	0	2[5]	flexible but not open policy, hours vary

[5] Zucker Hillside Hospital, a psychiatric hospital, does not have an ICU/CCU, and therefore could not be awarded points for the second half of the *Caregiver Policies* survey questions. For the *Caregiver Policies* survey, the maximum score Zucker Hillside Hospital was eligible for was 6 points, as opposed to 11 for other hospitals.

APPENDIX D

Scoring Guidance Notes
Policies on Family Caregiver/Care Partner 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 1.5 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 regarding 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.

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.

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.

APPENDIX E

Hospitals That Participated in IPFCC Learning Communities

Cohort 1

Alice Hyde Medical Center

Catskill Regional Medical Center

Champlain Valley Physician's Hospital

Clifton Springs Hospital

Elizabethtown Community Hospital

Faxton/St. Luke's/St. Elizabeth

Newark Wayne Community Hospital

Orange Regional Medical Center

Rochester General Hospital[6]

United Memorial Medical Center

Unity Hospital

Cohort 2 (Northwell Health hospitals)

Cohen Children's Medical Center

Glen Cove Hospital

Huntington Hospital

Lenox Hill Hospital

Long island Jewish – Forest Hills[7]

Long Island Jewish Medical Center

Long Island Jewish – Valley Stream Hospital

Northern Westchester Hospital

North Shore University Hospital

Peconic Bay Medical Center

Phelps Memorial Hospital

Plainview Hospital

Southside Hospital

Staten Island University Hospital

Zucker Hillside Hospital

[6] Rochester General Hospital is a part of Rochester Regional Health Network. While four other Rochester Regional hospitals were included in this survey analysis and the IPFCC program, Rochester General Hospital participated in the IPFCC program but was not surveyed.

[7] Long Island Jewish – Forest Hills became a participant in the IPFCC program after the initial fall 2018 survey. Although the hospital participated fully, its final scores could not be included in this report.

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.[8] 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.[9] Another study of patients who had the option found that a year later, the diminished anxiety and PTSD persisted.[10] 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.[11]

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 person[12] 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.[13] 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.[14]

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[8] C. Hanson and D. Strawser, "Family Presence During Cardiopulmonary Resuscitation: Foote Hospital Emergency Department's Nine-year Perspective," *J Emergency Nursing* 18:104-06 (1992).

[9] Patricia Jabre, *et al*., "Family Presence During Cardiopulmonary Resuscitation," *N Engl J Med* 368:1008-1018 (Mar. 14, 2013) (http://www.nejm.org/doi/full/10.1056/NEJMoa1203366#t=article).

[10] Patricia Jabre, *et al*., "Offering the Opportunity for Family to Be Present During Cardiopulmonary Resuscitation: 1-Year Assessment," *Intensive Care Med* 40(7):981-87 (July 2014)(https://www.ncbi.nlm.nih.gov/pubmed/24852952).

[11] Carolyn Bradley, *et al*., "Perceptions of Adult Hospitalized Patients on Family Presence During Cardiopulmonary Resuscitation," *Am J Critical Care* 26(2):103-110 (Mar. 2017) (http://ajcc.aacnjournals.org/content/26/2/103.short).

[12] J. Davidson, *et al*., "Clinical Practice Guidelines for Support of the Family in the Patient-centered Intensive Care Unit: American College of Critical Care Medicine Task Force 2004-2005," *Critical Care Medicine* 35(2):605-22, 613 (Feb. 2007) (http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.175.8195&rep=rep1&type=pdf, accessed July 27, 2017).

[13] M. Jain, M.D., "Intensive Care Units Grow More Friendly to Patients' Families at Some Hospitals," *Washington Post* (Aug. 29, 2011).

[14] D. Henderson and J. Knapp, "Report of the National Consensus Conference on Family Presence During Pediatric Cardiopulmonary Resuscitation and Procedures," *J Emerg. Nursing* 32(1):23-29 (Feb. 2006) (http://www.sciencedirect.com/science/article/pii/S0099176705007221, accessed July 27, 2017).

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