Difficult Decisions About Post-Acute Care and Why They Matter

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Introduction

As the decades-long trend of shifting care out of hospitals to lower-intensity settings continues, post-acute care (PAC)[i] has become a regular part of recovery for many patients who have undergone major surgery or experienced serious illness. Yet too often, the process of discharge planning can fail to help hospitalized patients and their family caregivers identify high-quality PAC providers that can best meet their needs for continued care. The system-centered interests of payers, providers, and regulators often take precedence over patients' needs—when the interests of patients, whose recovery is at stake, should be front and center. Support for careful assessment of PAC options, an ingredient that should be essential to discharge planning, is hard to come by and risky if missing.

To better understand these issues and their implications for improving communication, practices, and policies that can better support patient and family decisions, UHF has examined perspectives on discharge planning for PAC through a multifaceted project supported by the New York State Health Foundation. Over the course of this yearlong project, we engaged a wide range of stakeholders and subject matter experts in discussions about PAC decision-making and communication gaps and scanned related literature, regulations, and publicly-available quality information. The methods we used to conduct our study are outlined in Appendix A.

DIFFICULT DECISIONS

The **Difficult Decisions** series examines the challenges faced by patients who need post-acute care after hospital stays for major surgery or serious illness. Prepared by the United Hospital Fund and supported by the New York State Health Foundation, the reports in this series cover the many factors that go into hospital discharge planning, with context for patients and their families, for hospital teams, and for policymakers.

This first report in the series takes a broad look at what makes informed decision-making about post-acute care so challenging. Forthcoming reports will focus on the experiences of patients and family caregivers, the perspectives of health care providers, and the best practices, innovations, and policy levers that could help support New Yorkers who need to make decisions about post-acute care.

i According to the Centers for Medicare & Medicaid Services, post-acute care includes services delivered by four types of providers–skilled nursing facilities, home health agencies, inpatient rehabilitation facilities, and long-term care hospitals. The same definition of PAC is used throughout this report.

The Context for PAC Decision-Making

As hospital stays have shortened, PAC has become a growing component of the U.S. health care system. Approximately one in five hospitalized patients in the U.S.[1] and one in four patients in New York State[2] continue their recovery at a skilled nursing facility (SNF), inpatient rehabilitation facility, or long-term care hospital—or at home with nursing and other services provided by a home health agency (HHA). Many more patients and family caregivers are now faced with making decisions about PAC settings and providers soon after a hospital admission,[ii] although they might not be familiar with what those services entail or what their health insurance may cover.

Because the quality of care varies among providers, decisions about where to receive PAC can have serious consequences for patients and families, including adverse outcomes and steep out-of-pocket costs. Yet it is often difficult for patients and families to identify the best options and make informed decisions. Further, for many New Yorkers, those options can be constrained by a host of factors (see box).

Decision-making about PAC can be challenging for anyone who is ill enough to be hospitalized or their family caregivers, but even more daunting for elders or those with complex medical needs or cognitive impairment. Uneven quality across PAC settings and lack of evidence as to what care setting works best for which patients are well documented.[3,4,5,6,7] Given these uncertainties, and multiple providers to choose from in many geographic areas, patients and families are often poorly positioned to determine what care options are best for them.

While diligent and well-intentioned hospital staff, especially case managers and social workers, devote significant effort to arranging safe and appropriate discharge plans, the onus of evaluating and choosing a PAC provider is placed on patients and families. Informed decision-making can involve searching several sites on the Internet, sifting through pages of highly technical quality information, seeking recommendations from family and friends or

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External Factors That Can Limit PAC Options

- Insurance Constraints
  - Type of health insurance coverage
  - Benefit limits for PAC services – e.g., number of days or visits covered
  - Authorization requirements
  - Narrow provider networks
  - Definitions of medical necessity that are subject to interpretation
  - Lack of insurance
- Capacity Constraints
  - Supply and capabilities of providers in a geographic area, including home health nurses and aides
  - Availability of community services and supports
- Other System Constraints
  - PAC admission criteria
  - Relationships between referring physicians/hospitals and PAC providers, e.g. participants in Medicare's Comprehensive Care for Joint Replacement program or other bundled payment models

Source: United Hospital Fund Analysis, 2018.

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ii The shift of hospitalized patients who are no longer acutely ill to SNFs and to home with home and community-based services is discussed in Barnett M, Grabowski D, and Mehrotra A. 2017. Home-to-Home Time—Measuring What Matters to Patients and Payers. *NEJM* 377:4-6.

advice from a primary care physician, touring facilities, and weighing the advantages and disadvantages of multiple options.

This time-sensitive process must often be completed within 24–48 hours, which can overwhelm sick patients and family caregivers, especially during a medical crisis. Yet little support is provided to help them understand tradeoffs and make the best choice for their situation – an even greater burden for patients and family caregivers with low literacy, numeracy, or Internet skills, or for those with limited English proficiency or lack of access or familiarity with the Internet.

> *"There are few evidence-based guidelines for PAC, so it is not always clear when PAC is needed, where care is best provided, how much care is required, or when more care is likely to result in better outcomes. PAC placement decisions often reflect nonclinical factors… but not necessarily where the patient would receive the best care."*
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> *Medicare Payment Advisory Commission Report to the Congress: Medicare Payment Policy, March 2018, p. 191.*

Most patients and families want hospital staff to assist them with decisions about where to go for care.[8,9] But as described further on in this report, federal law and regulations that guarantee Medicare beneficiaries choice of participating providers and prohibit hospitals from recommending specific providers can stand in the way[10,11]—a central dilemma that lies at the heart of discharge planning for PAC.

Why Decisions About PAC Matter

PAC is a high-volume and high-expenditure component of the U.S. health care system. Each year, over 8 million Americans require PAC following a hospitalization. Medicare, the nation's largest health care payer, covers most PAC services through its Original Medicare program.[iii] Medicare Advantage plans, Medicaid, and other commercial health plans cover the remainder. In 2016, two of every five hospitalized patients with Original Medicare were discharged to PAC settings (mostly to SNFs or HHAs) at a cost to the federal government of over $60 billion.[12] In New York State alone, nearly 300,000 Original Medicare beneficiaries received SNF or HHA services at a cost exceeding $2.9 billion.[iv,13]

The demand for PAC is likely to grow as more New Yorkers live into their 90s and beyond with chronic conditions, and the state's baby boomers age.[v] With more than 620 nursing homes, 120 certified home health agencies, and 1,400 licensed home care services agencies in New York,[14,15] the supply of providers for PAC is large enough in many areas to offer a range of choices to patients and families.

Why Decisions Can Be Difficult

Patients who need PAC are among the most sick and vulnerable in our health system, with common chronic conditions such as arthritis, heart failure, stroke, renal failure, and chronic obstructive pulmonary disease.[16] Some have conditions or situations that make them more difficult to place in PAC settings (see box).

Individual Factors That Can Limit PAC Options

Medical

- Need for specialized services not commonly available, such as dialysis or bariatric services
- Ventilator dependency
- Expensive drug regimens, such as cancer drugs or intravenous antibiotics
- Mental health or substance use disorders
- Cognitive problems or dementia
- Patients who are likely to need long-term care following post-acute care

Social

- Age (i.e., younger patients)
- Immigration status
- Unstable housing or homelessness
- Behavioral issues
- Limited social support

Source: United Hospital Fund Analysis, 2018.

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iii Also known as Medicare fee for service (FFS), which covers approximately 85% of patients who receive PAC in a SNF and 65% who receive PAC at home. Tian W. An All-Payer View of Hospital Discharge to Postacute Care, 2013. Healthcare Cost and Utilization Project Statistical Brief #205. May 2016. Agency for Healthcare Research and Quality, Rockville, MD, p. 3.

iv In 2017, 62% of New York State Medicare beneficiaries were enrolled in Original Medicare and 38% in Medicare Advantage plans. Kaiser Family Foundation, Medicare Advantage 2017 Spotlight: Enrollment Market Update, https://www.kff.org/medicare/issue-brief/medicare-advantage-2017-spotlight-enrollment-market-update/ accessed April 27, 2018.

v By 2030, baby boomers in New York State will be aged 66-84. Projections indicate that the percentage of people aged 65+ may climb from 14.7% to somewhere between 17% to 19%, while the number of New Yorkers aged 85+ may grow to more than 500,000 people. U.S. Census Bureau, American Fact Finder, https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=CF, accessed Aug. 27, 2018. U.S. Census Bureau, The Baby Boom Cohort in the United States: 2012 to 2060, Current Population Reports, May 2014. New York State Department of Labor, http://pad.human.cornell.edu/counties/projections.cfm, accessed Aug. 27, 2018. New York State Office for the Aging, County Data Book, https://aging.ny.gov/ReportsAndData/2015CountyDataBooks/01NYS.pdf accessed Sept. 12, 2018.

In the hospital setting, the decision to discharge a patient can evolve rapidly, sometimes taking patients and family caregivers by surprise, while they are still focused on the medical problem that caused the hospitalization. Many people are not familiar with PAC services and have little sense of the limitations of their health insurance, and "advance planning" for PAC is rarely done. Yet, time and cost pressures can lead to rushed processes that push patients and family caregivers to make rapid decisions. Under these circumstances, it seems unrealistic to expect them to identify and assess care options quickly without much help from members of their hospital care team.

> *"Most patients select a facility based on its location, perhaps because they are not provided with quality information or advice."*
> *Emily Gadbois, Denise Tyler, and Vincent Mor.*
> *Selecting a Skilled Nursing Facility for Postacute Care:*
> *Individual and Family Perspectives. JAGS 65:2463, 2017.*

Although patients and family caregivers often ask discharge planning staff for help, they do not commonly receive the guidance or advice they seek. Patients who will be discharged to home with certified HHA services are generally given a list of the names, addresses, and phone numbers of agencies in the surrounding area and asked to choose an agency. When PAC at a facility is required, discharge planners distribute similar contact lists for SNFs located in the region, indicate which ones accept a patient's insurance, and ask patients to identify several choices. Some discharge planners will share what they know about providers on the HHA and SNF lists, but many others do not due to concerns about complying with legal regulations and a lack of knowledge about provider quality of care.[17,18,19]

The PAC Quality Conundrum

The stakes are high in decision-making about PAC. Patients who receive care from lower-quality PAC providers have higher rates of complications and rehospitalizations and worse outcomes, which in turn contribute to rising costs.[20,21,22] Yet many patients and families may not be aware that quality of care varies among PAC providers or that discharge to a higher-quality provider could be an option.

Research has shown that most people select SNF providers near their home or their family, although others place higher value on quality of care and will travel further to receive it.[23,24] For those who need HHA services at home, decision-making is often based on the location of or previous experience with an agency, or whether the hospital has an affiliated HHA.[25] A recent Medicare Payment Advisory Commission (MedPAC) analysis found that 84% of Medicare beneficiaries had at least one higher-quality SNF near the one where they received care. Similarly, 94% of beneficiaries who received HHA services had at least one other agency within a 15-mile radius with a higher quality rating.[26] Still few of the provider lists that hospital discharge planners distribute

to patients and family caregivers contain comparative quality data, although this is slowly starting to change in New York.[vi]

When patients and families choose PAC settings and providers that do not match their needs and are not of high quality, risks rise for rehospitalizations, emergency visits, declines in physical or psychological function, lengthy stays in a SNF, increased likelihood of becoming a nursing home resident, and mortality.[27,28,29] Such poor outcomes exact a toll on patients and families and drain our collective health care resources. When there is so much skin in the game, supporting decisions that help place the right patients in the right setting at the right time seems essential—and requires helping patients and family caregivers understand the full range of facility- and community-based care options available to them.[vii]

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vi For example, provider lists used by discharge planners at one major health system in New York display the overall Medicare star rating for each SNF.

vii For example, SNF, certified HHA services, adult day health care, assisted living options, licensed home care service agency services, Nursing Home Transition and Diversion Waiver program, Programs of All-Inclusive Care for the Elderly, Special Needs Plans, hospice services, and others. See LeadingAge New York, Home and Community-Based Service Options for Seniors and Adults with Disabilities, October 2018 at https://www.leadingageny.org/providers/home-and-community-based-services/hcbs-service-options/, accessed Nov. 8, 2018.

Where New Yorkers Can Find Out About PAC Quality

Uneven quality persists in New York's health care system, as it does throughout the United States. While many PAC providers in New York deliver consistently excellent care, others do not. Choosing carefully can mean the difference between recovering fully, cycling in and out of health care facilities, or becoming a long-term resident of a nursing home.

The good news is that there is a significant amount of quality information about PAC settings and providers on the Internet. The bad news is that this information is not especially helpful for identifying and assessing which services or care setting would be most beneficial to an individual patient's recovery. Further, the information is scattered, collecting it takes time and effort, interpreting it can be difficult, and doubts about its validity and reliability abound. Studies suggest that patients are not always aware of publicly available quality information and can find the information difficult to understand.[30,31] Not all patients and families are fully comfortable searching the Internet for medical information or interpreting what they find. And even those who are Internet savvy and can interpret quality information may not find much value in what's available, depending on their individual situations and preferences.[32]

Several websites can help New Yorkers research and compare the quality of PAC providers. Overviews follow.

The "Compare" Websites

Most hospital discharge planning staff refer patients and family caregivers to the "Compare" sites for HHAs and nursing homes that are sponsored by the Centers for Medicare & Medicaid Services (CMS). Home Health Compare contains performance ratings for all Medicare-certified HHAs based on data from insurance claims, standard patient assessments that agencies submit to CMS, and other information collected by state regulators and CMS. The site displays two "star

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Examples of Gaps in Quality Information on Nursing Home Compare

Provider Information
- On-site presence of MDs and nurses
- Staffing levels for short-stay v. long-stay units, and turnover rates
- Staff qualifications and training
- Languages spoken by staff and cultural attentiveness
- Therapy frequency and schedule

Patient and Family Experience
- Reviews and comments from other patients and families
- Staff responsiveness and attentiveness
- Cleanliness and smell
- Food quality and appropriateness

Outcomes and Costs
- Condition- specific outcomes (e.g., stroke), customized information for "patients like me"
- What care insurance covers
- Out-of-pocket costs

Source: United Hospital Fund Analysis, 2018.

ratings"—one on quality of care and one on patient experience[viii]—that can help consumers[ix] compare an agency's performance with others.

Launched 20 years ago to help consumers identify high-quality nursing homes, [Nursing Home Compare](#) is the main source for report cards on all Medicare- and Medicaid-certified nursing homes in the United States, which include those that provide PAC services. The site displays "star ratings" based on the results of state health inspections and information that nursing homes submit to CMS on staffing levels and performance on quality measures (a more detailed description of the star ratings follows).[x] While this may sound comprehensive, there are gaps that limit its value to consumers such as ratings on patient experience measures[xi] and other quality information that patients and family caregivers find meaningful.[33,34,35,36,37,38] (see box for examples and a more detailed list of the information that may be of interest to patients and family caregivers in Exhibit 1). Moreover, the kinds of information that matter most to consumers can also vary by race and ethnicity.[39]

Exhibit 1. Examples of Information That May Interest Patients and Family Caregivers Who Are Considering PAC in a SNF

SNF Structural Characteristics	
Ownership	Religious affiliation/services
Management and reputation	Visiting hours
Hospital affiliation	Staffing
Facilities	-Qualifications and training
-Appearance of facility—e.g., age, state of the art	-Language and cultural competencies
-Cleanliness/smell	-Adequacy
-Safety and security	*On site physicians and nurse practitioners*
-Size/bed availability	*Access to specialists—geriatrics, other medical specialties, mental health, nutrition*
-Private room availability	*Physical therapy*
Gestalt—overall sense of the facility, what it's like there	*Nurse staffing*
Race and ethnicity, languages, religion of patient population	*Weekend coverage*
Access to public transportation/parking	
Concerns About Services Provided	
Access to specialized services	Schedule of therapy and other services
Medication/pharmacy policies	Activities available
Types of therapy available	Quality of and culturally appropriate food
Quality Concerns	
How PAC services will benefit a patient	Interpersonal characteristics of staff
Care coordination with hospital staff and physician offices	-Friendly
Pending lawsuits	-Competent
Condition-specific outcomes	-Responsive
Pain management skills	-Degree and skill at interacting with patients and family caregivers
Quality and service ratings	
Patient and family reviews	
Other Influences	
Recommendations/prior experience of family/friends	Recommendation from physician or other health care professional
Proximity to family/home	

Sources:

Castle NG. June 2003. Searching for and Selecting a Nursing Facility. *Medical Care Research and Review* 60(2): 236-7.

Hefele J et al. June 2016. Choosing a Nursing Home: What Do Consumers Want to Know, and Do Preferences Vary across Race/Ethnicity? *Health Services Research* 51(3): 1167-87.

McGarry B. and Grabowski D. August 29, 2017. Helping Patients Make More Informed Postacute Care Choices. *Health Affairs* Blog.

Mukamel D, Amin A, Weimer D, et al. When Patients Customize Nursing Home Ratings, Choices and Rankings Differ from the Government's Version. *Health Affairs* 35(4): 714-9.

Sefcik J, Nock R, Flores E, et al. 2016. Patient Preferences for Information on Post-Acute Care Services. *Research in Gerontological Nursing* 9(4): 175-82.

Shugarman LR and Brown JA. 2006. *Nursing Home Selection: How Do Consumers Choose? Volume I: Findings from Focus Groups of Consumers and Information Intermediaries.* RAND Corporation.

Medicare Star Ratings. CMS uses "star ratings" on all the "Compare" websites to rate health care providers. The five-point scale used on Nursing Home Compare is known as the CMS Five-Star Quality Rating System.[xii,40] Although these ratings are the best currently available to the public, the data sources and methods used to produce them have been subject to controversy.[41] Flaws and gaps have been raised by experts in quality measurement, and the ratings have been criticized by providers and advocates alike for their reliance on self-reported data, which can open the door to possible manipulation and rating inflation.[42,43,44,45]

The star rating for staffing, perhaps the most salient for consumers, is also the most contentious. Over the years, the media has drawn extensive public attention to inadequate staffing and quality problems in nursing homes.[xiii,46] Staffing levels are a structural aspect of quality that patients and family members can assess for themselves and frequently inquire about when choosing a PAC provider.[47,48] Before 2018, the staffing data and star ratings that appeared on Nursing Home Compare were based on unverified, self-reported data from SNFs. Staffing ratios calculated from verifiable, payroll-based journal reports[xiv] were posted for the first time on Nursing Home Compare in July 2018 and led to the downgrading of star ratings for staffing in 9% of the nation's SNFs.[49]

While these newly available staffing data represent an important and overdue improvement in transparency, a major limitation remains. Nursing Home Compare displays staffing data for the entire facility (short- and long-stay units combined) and does not separate the data for the short-stay units where most patients receive PAC.

Takeaways on the Compare Sites for PAC. Over the years, numerous experts and organizations have weighed in on weaknesses in the data that appear on Nursing Home Compare, Home Health Compare, and CMS's other Compare sites, as well as their usefulness to consumers. In response, CMS continues to improve the sites. Recent changes to the Nursing Home Compare home page and search functions make it easier for consumers to review and sort through an initial list of providers based on distance and star rating category—overall and separately for inspection results, staffing, and quality measures. Users can also filter results by overall star rating as well as several nursing home characteristics, such as whether they are located within a continuing care

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xii The Five Star System assigns each nursing home an overall star rating based on separate ratings for three domains of quality: ratios of staff members to residents, residents' clinical outcomes, and the results of regulatory inspections. The overall rating combines the three domains with the greatest weight given to the inspection rating. For more information, see https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandComplianc/FSQRS.html

xiii Longstanding differences in staffing levels between for-profit and not-for-profit nursing homes have been documented. For example, Rau and Lucas. July 27, 2018. Medicare Slashes Star Ratings for Staffing at 1 in 11 Nursing Homes. *New York Times*. A recent study that examined performance results on three new short-stay nursing home quality measures on Nursing Home Compare found that nonprofit status was associated with better performance. See Saliba D, Weimer DL, Shi Y, and Mukamel DB. 2018. Examination of the New Short-Stay Nursing Home Quality Measures: Rehospitalizations, Emergency Department Visits, and Successful Returns to the Community, *Inquiry* 55: 1-11.

xiv For registered nurses, licensed practical nurses and licensed vocational nurses, and nurse aides. In 2015, CMS began requiring nursing homes to report hours worked through an electronic payroll-based journal system.

retirement community or hospital, or whether they accept Medicare or Medicaid. In addition, CMS released performance results on Nursing Home Compare in October 2018 for five new, short-stay quality measures.[xv]

However, some shortcomings remain:

- Clinical quality measures continue to predominate, and less attention is given to aspects of quality that patients and families find meaningful—such as quality of life; care coordination; and communication among staff, patients, and family members[50]

- Poor reliability and high variability of state SNF inspection data[xvi,51]

- Data that are not timely and depict a point in time rather than the current state of HHA or SNF quality[52]

- Methods that are too complex for most consumers to grasp

- Information that is available only in English

Although Nursing Home Compare attracts more than 150,000 visits per month, and Home Health Compare over 30,000, little is known about what information consumers find on these sites and how they use it for making decisions. Studies have shown that although Internet research is one of several ways that people gather information when faced with a decision about PAC, the public is not highly aware of Nursing Home and Home Health Compare, and the star ratings have not led to greater use of high-quality providers.[53]

New York State Health Profiles

Web pages sponsored by the New York State Department of Health (NYSDOH) on Health Profiles[xvii] contain performance results on quality measures for SNFs and certified HHAs that come from data collected by CMS, along with a few additional features that consumers might find useful. For example, a drop-down menu of specific services can be used to search for nursing homes or home care agencies. There are no limits on the number of providers that can be compared at one time, and a single graph

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xv These measures are being used by CMS in the SNF Quality Reporting Program and include percentages of SNF residents who developed new or worsened pressure ulcers, had one or more major falls with major injury, whose functional abilities were assessed and functional goals included in their treatment plan, who successfully returned to home and community, and Medicare spending per beneficiary. For more information, see https://www.cms.gov/newsroom/fact-sheets/skilled-nursing-facility-snf-quality-reporting-program-qrp-data-nursing-home-compare, accessed Oct. 26, 2018.

xvi CMS rolled out a new inspection process in November 2017 that will take about a year to fully implement. While summaries from the new inspections are being posted on Nursing Home Compare as they occur, the findings from the new inspections are not yet being used to calculate nursing home star ratings. Instead, the inspection rating is based on the two most recent inspections prior to November 2017 and inspections due to complaints in the last two years prior to November 2017. For more information, see https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandComplianc/FSQRS.html, accessed Sept. 6, 2018.

xvii https://profiles.health.ny.gov/, accessed on July 10, 2018.

for each quality measure displays results for every provider in the state. However, Health Profiles for nursing homes does not contain staffing data.[xviii]

Until August 2018, the performance of nursing homes on short-stay and long-stay quality measures could be found separately on both Nursing Home Compare and Health Profiles.[xix] However, recent changes to Health Profiles for both Nursing Homes and Home Care combine results on the CMS quality measures for SNFs and certified HHAs into new "domains" with their own star ratings.[xx] For nursing homes, the NYSDOH created five domains with a mix of short- and long-stay measures including preventive care, quality of care, quality of life, resident safety, and resident status.[xxi] The new domains for home care include managing daily activities, managing pain and treating symptoms, patient satisfaction, preventing harm, and preventing unplanned hospital care.[xxii] The Health Profiles web pages for nursing homes and certified HHAs display a star rating for each domain as well as an overall star rating.[xxiii]

xviii More information about the contents of Nursing Home Compare and Health Profiles can be found in Appendix B of this report.

xix Short-stay measures show the average quality of care for those who stayed in a SNF for less than 101 days; long-stay measures, for those who stayed 101 days or more.

xx The new DOH star ratings differ from those that appear on CMS Nursing Home Compare and Home Health Compare.

xxi For more information, see https://profiles.health.ny.gov/news/view/30.

xxii For more information, see https://profiles.health.ny.gov/news/view/29.

xxiii The overall star ratings for nursing homes and certified HHAs are normalized based on their average score across the domains. For more information and the methodology used by NYSDOH, see https://profiles.health.ny.gov/nursing_home/pages/methodology/ and https://profiles.health.ny.gov/home_care/pages/methodology/.

Other Websites

New York consumers who want to learn more about PAC providers can visit additional sites such as those of their health plans, social media, Long-Term Care Community Coalition (LTCCC), and ProPublica (see box). Additionally, the NYSDOH conducts an annual quality and performance evaluation project to improve the quality of care for residents in Medicaid-certified nursing facilities. The project ranks New York State facilities in quintiles based on their performance on 15 quality measures, inspections and deficiencies, and reporting compliance. Quality of care is assessed based on 11 long-stay quality measures including several that do not appear on Nursing Home Compare such as potentially avoidable hospitalizations, percent of contract agency staff used, and rate of staffing hours per day. The rankings, which are publicly reported on a different page of the NYSDOH website, could aid decisions about PAC but may be more relevant when the need for long-term care in a nursing home is likely.[54]

> **Other Websites with PAC Quality Information**
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> - Health plan websites for PAC benefits, in-network providers, and any information they may have about quality and costs
> - LTCCC, for useful information about nursing home quality in New York including enforcement actions, fines, penalties, alerts, poor performers (e.g., special focus facilities), special reports, quality information from CMS, Medicaid rates, and more
> - ProPublica's Nursing Home Inspect tool for easy searches (by name of facility, city, or keyword) of CMS data that are assembled from inspection reports from the past three years and related fines
> - NYSDOH Nursing Home Quality Initiative for performance rankings of Medicaid-certified nursing homes
>
> Source: United Hospital Fund Analysis, 2018.

Consumer reviews on Yelp and Facebook have gained in popularity as a source of information about the quality of SNFs and HHAs. A recent study showed that Yelp reviews about nursing homes captured information about aspects of care not reported elsewhere, including staff responsiveness, caring, and professionalism, concerns about the appearance of the facility and its environment, and financial issues, among others.[55] However, until the numbers of consumer reviews grow, they can be subject to bias and should be interpreted with caution.

What Performance Results Reveal
About the Quality of PAC in New York State

Although a PAC provider's performance on quality measures may not be top of mind for New York consumers, persistent variation in these measures makes a strong case for their consideration. At SNFs in New York, rehospitalization rates range from 3% to 35%. Performance also ranges on other short-stay performance measures—such as emergency department visits, and patients reporting moderate to severe pain, improvement in function, or successful discharge to community.[xxiv,56] Performance rates vary for long-stay quality measures as well—for example, for residents who lost too much weight or experienced depressive symptoms, pressure ulcers, or moderate to severe pain. The performance of certified HHAs varies too, for example, on measures such as patients whose walking improved, rehospitalizations, patients who needed urgent or unplanned medical care, and the rate of patients who would definitely recommend the HHA to friends and family.[57]

"The bottom line is that all these sources have dismaying limitations. Experts advise starting your investigation online, using Yelp and other consumer reviews—and Nursing Home Compare and Nursing Home Inspect, and talking to friends and relatives who've had recent experience with local facilities."
Paula Span, "No Luck Finding the Right Nursing Home? Maybe Yelp Can Help," New York Times, May 11, 2018.

The graphs that follow provide examples of the degree of performance variation on quality measures by PAC providers in the state based on data displayed on Health Profiles. Additional statewide performance results on SNF and certified HHA quality measures appear in Appendix B.

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xxiv Some of this variation reflects differences in the mix of short-stay patients and long-term residents. Some facilities have large proportions of short-stay SNF patients who are expected to be discharged to the community, while others serve mostly long-stay residents who are not expected to be discharged.

Performance Ranges of New York State Skilled Nursing Facilities on Short-Stay Quality Measures (High, Low, and Statewide Mean)

━ High ━ Low ━ NYS Mean

	Rehospitalization Rates	Emergency Department Visits	Pts Reporting Moderate to Severe Pain	Improvement in Function	Successful Discharge to Community
High	36%	27%	41%	100%	86%
NYS Mean	20%	10%	9%	70%	55%
Low	3%	0%	0%	7%	0%
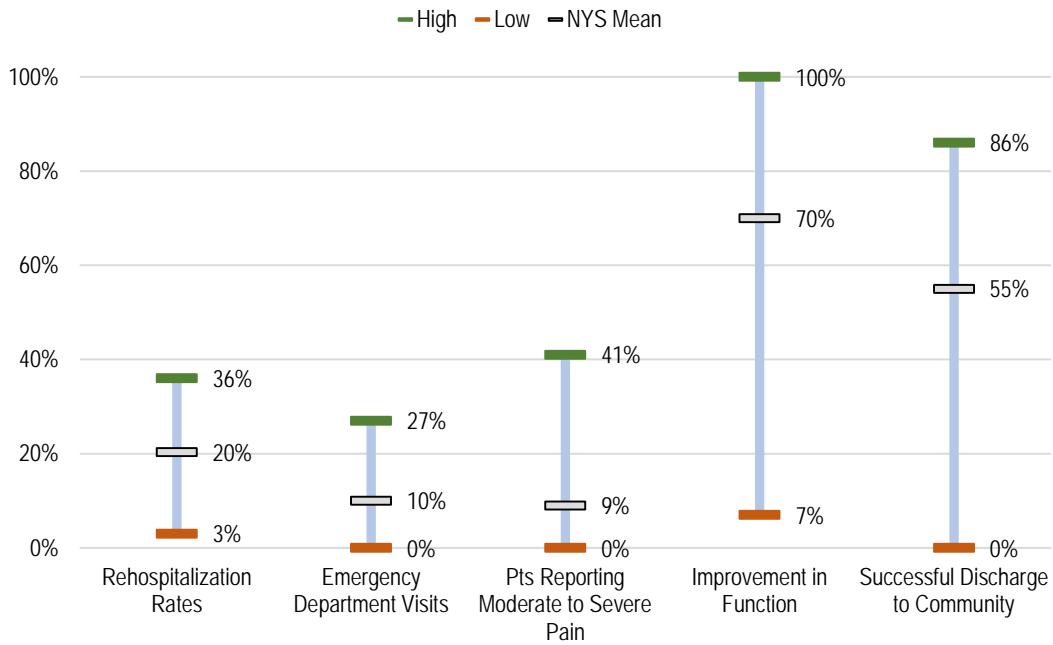
Performance Ranges of New York State Skilled Nursing Facilities on Long-Stay Quality Measures (High, Low, and Statewide Mean)

━ High ━ Low ━ NYS Mean

	Residents Lost Too Much Weight	Residents Experienced Depressive Symptoms	Residents Had Pressure Ulcers	Residents Reported Moderate to Severe Pain
High	20%	90%	27%	19%
NYS Mean	6%	7%	7%	4%
Low	0%	0%	0%	0%
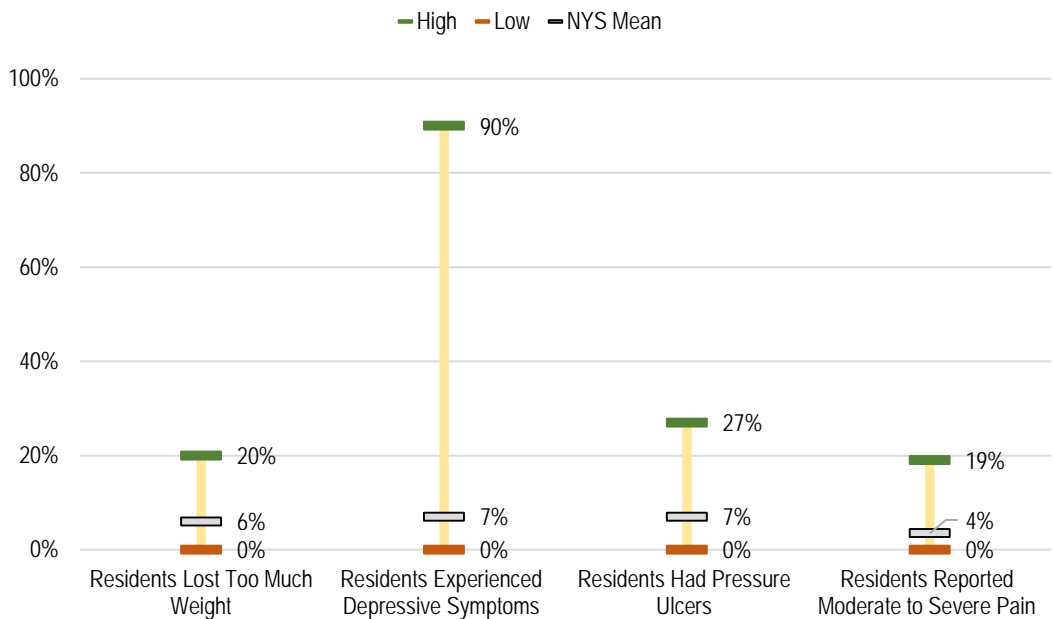
**Performance Ranges of New York State Certified Home Health Agencies
on Quality Measures (High, Low, and Statewide Mean)**

― High ― Low ― NYS Mean

100%			
100%			95%
80%			
73%			72%
60%			
40%			
32%			
23%	20%		
16%	11%		
20%	4%		
0%	0%		0%

Pts Whose Walking   Rehospitalization Rates   Pts Needing Urgent,   Rate of Recommendation
Improved   Unplanned Medical Care   to Friends & Family
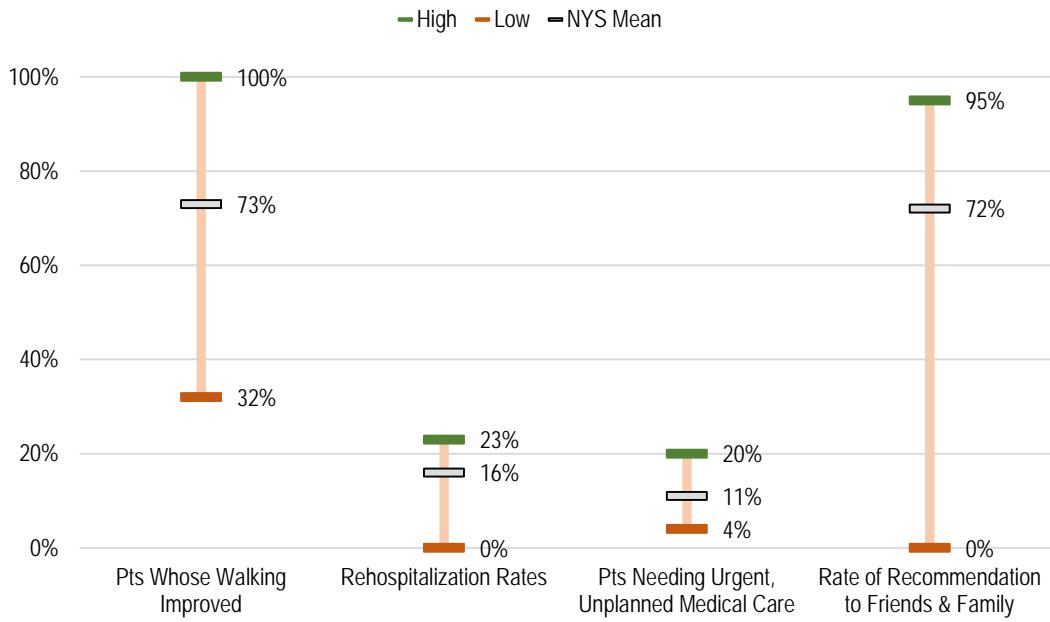
How the Health System Helps and Hinders PAC Decisions

Legal frameworks, payment policies, and provider processes all play a role in influencing hospital discharge planning and PAC decision-making. The following overview describes how each can facilitate or limit the support that hospital staff can provide, and the just-in-time decisions that patients and family caregivers must make about PAC. Additional discussion of how regulations affect hospital discharge planning for PAC will appear in a forthcoming report.

Relevant Statutes and Regulations

A patchwork of federal and state statutes and regulations related to discharge planning and post-discharge care have been implemented over the past 50 years to help clarify and protect the rights of hospitalized patients and their family caregivers. These include the federal Anti-Kickback Statute [42 U.S.C. § 1320a-7b(b)],[58] Section 1802 of the Social Security Act,[59] the federal Conditions of Participation (CoPs) that hospitals must meet to participate in the Medicare program,[60] the New York Codes, Rules, and Regulations (NYCRR Title 10 Part 405.9),[61] and New York State's Caregiver Advise, Record, and Enable (CARE) Act of 2014.[62],[63]

When considered together, this legal framework protects the rights of:

- Medicare beneficiaries to choose among participating medical providers[xxv] and to be safeguarded from referral decisions influenced by any form of remuneration

- Patients and their family caregivers to receive advanced notice of discharge from the hospital and to appeal the discharge plan if they disagree

- Patients to remain in the hospital until the discharge plan is in place

- Patients and family members or designees to be involved in discussions about the need for PAC and planning for discharge, and to be prepared for post-discharge care

    The discharge planning regulations that are part of this legal framework (the CoPs and NYCRR Title 10 Part 405.9) place related requirements on hospitals and their staffs including the provision of certain information to help patients and family caregivers make decisions about PAC providers. For example:

- Hospitals must respect patient preferences and involve patients and family caregivers in discharge planning[64]

- Hospitals must supply lists of local Medicare- and Medicaid-participating SNFs and certified HHAs to patients when PAC services are indicated. In New York, they must involve patients and their family/representative in selection of PAC when

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xxv However, the Social Security Act doesn't require participating providers to serve the patients who have selected them.

needed, and supply information to them about the range of PAC services available in their community[65]

- Hospitals may not specify or otherwise limit the eligible providers that are available to the patient and must disclose financial interests in any HHA or SNF to which a patient is referred[66]

Not surprisingly, there are also limitations and gaps in patient choice protections. Patients in managed care plans, such as Medicare Advantage and Medicaid Managed Long-Term Care in New York, have fewer options—they must choose a provider in their health plan's network for PAC services to be covered. No matter the type of insurance, PAC providers are not obligated to accept patient referrals. In other words, regulations protect choice but not access to care.

An additional but more nuanced federal regulation permits *but does not require* hospitals to refer patients to the CMS Compare websites or official state websites for more information about PAC providers and help patients find or interpret quality-related information. This distinction between *permitting* and *requiring* the provision of information about PAC providers can get lost on the ground, when hospitals concerned about compliance may err on the side of legal caution. Narrow interpretation of the regulations has led many discharge planners on the frontlines to be cautious about providing much assistance or advice to patients and families beyond distributing lists of providers.[67,68] The unintended effect has been to make potentially useful information harder to find and interpret.

To address this shortcoming, the Improving Medicare Post-Acute Care Transformation (IMPACT) Act of 2014 proposed changes to the discharge planning regulations that would require hospitals to assist patients, their families, or the patient's representative in selecting a PAC provider by using and sharing provider-specific quality information relevant to patient goals of care and treatment preferences.[69] To date, those proposed changes have not been finalized; CMS has until November 2019 to issue a final rule.[70] In the meantime, patients and family caregivers are left to muddle through.

The Bottom Line. Existing legal safeguards, although essential to effective discharge planning, don't go far enough to support patients and family caregivers in assessing their options and choosing high-quality PAC providers.

Payment Policies

When it comes to PAC, the interests of payers also factor into the discharge planning equation. Legitimate business concerns, to ensure that health plan members receive safe and appropriate care in lower-intensity settings, can facilitate timely discharge planning—but also sometimes hinder it.

For hospitalized patients who choose to go home with services provided by a certified HHA, discharge planning is frequently straightforward. But it can also involve some back and forth among hospital staff, patients and families, and health plan care

managers to clarify which services are covered and which providers are "in network." These can be common sources of misunderstanding, since people generally lack familiarity with their insurance benefits for PAC. However, it can be difficult for patients and families to know, in advance of a medical need, what services will be covered and for how long.

For managed care enrollees who need to recover in a SNF, payer concerns can influence PAC options and the discharge planning process itself, especially when patients have complex needs or multiple chronic conditions. The tools that payers use to control PAC utilization (e.g., determinations of medical necessity and prior authorization requirements), and concerns about potential rehospitalizations or avoidable emergency visits, can delay the discharge planning process. When this happens, patients remain in the hospital and families wait.

The Complexity of Discharge Planning

In response to financial incentives from new value-based payment methodologies, hospitals and health systems are paying even closer attention these days to ensuring that patients are discharged promptly to the most appropriate care setting. Still discharge planning remains complicated, lacks standardized protocols, and varies from patient to patient and hospital to hospital.[71,72]

For some hospitalized patients and their family members, the discharge planning process works well – they experience relatively smooth transitions to PAC and full recoveries. For others the road can be rougher,[xxvi] and quality of care can suffer along the way. Either way, discharging to PAC always involves substantial documentation, multiple parties using multiple channels of communication, and sometimes even contingency planning (e.g., when it is unclear during the hospitalization whether a patient will recover sufficiently to be able to be discharged to home). A host of factors can converge to influence any individual's discharge plan, among them:

- a patient's short- and longer-term care needs, insurance coverage, home environment, and social support

- patient and family caregiver priorities and preferences and how well those are aligned

- the knowledge and skills of a discharge planner

- hospital interpretations of statutes and regulations related to discharge planning and views about compliance

xxvi A recent study of patients newly admitted to SNFs for PAC found that most reported negative experiences with decision-making and felt unprepared, unassisted, and rushed. Patients also reported that hospital staff were minimally involved in SNF selection and that they would have appreciated more help from discharge planners. Gadbois E, Tyler D, and Mor V. 2017. Selecting a Skilled Nursing Facility for Postacute Care: Individual and Family Perspectives, *JAGS* 65:2459-65.

- the degree of length of stay pressures within individual hospitals (e.g., high occupancy rates, patients in the emergency department awaiting admission, financial concerns)

- a health system's level of vertical integration and participation in value-based models

Decision-Making Amid the Shifting Landscape of PAC

New payment models that place health systems at financial risk for the care delivered beyond their walls are pushing them to align with higher-quality PAC providers to better manage and coordinate care and move it to lower-cost settings.[xxvii] Health information technology incentives and broader adoption of new care management platforms and tools may also help introduce and balance the standardization and customization that are needed for more rational and efficient discharge planning. In 2019, CMS will launch the first value-based program for SNFs aimed at reducing 30-day readmissions[xxviii] as well as a new case-mix model that seeks to shift Medicare payment away from service volume and toward prioritizing patients' conditions and related care needs.

Such system-centered changes could be welcome steps if they reduce the burden of decision-making on patients and family caregivers and lead to higher-quality PAC. But until more evidence emerges, we won't know what influence these changes will have. For instance, will patients and family caregivers have fewer PAC options and less access to the full range of care needed to complete their recovery? Will their discharge planning experiences improve so that they have fewer regrets about their PAC decisions?[xxix] Will their PAC outcomes improve so that patients are at less risk of complications or long-term care placement?

While new payment models and incentives hold promise for improving PAC, they alone will not be sufficient to achieve the aim of placing patients at the center of discharge planning decisions. Forthcoming reports in this series, which will look in greater depth at hospital discharge planning for PAC from the perspective of patients and family caregivers and the health care providers who serve them, should shed additional light on the barriers to informed decision-making—and opportunities for supporting it.

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xxvii These include Medicare's initiatives for Comprehensive Care for Joint Replacement, Bundled Payments for Care Improvement, Accountable Care Organizations, and other episode-based payment reforms.

xxviii The program creates an incentive pool by holding back a small portion of SNF payment. For more information see https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2018-Fact-sheets-items/2018-04-27-4.html, accessed Aug. 2, 2018.

xxix For an analysis of the decision outcomes of patients and family caregiver decisions about PAC, see Burke RE, Jones J, Lawrence E, et al. 2018. Evaluating the Quality of Patient Decision-Making Regarding Post-Acute Care, *JGIM* 33(5): 678-684.

Appendix A. Methods

Over the course of this project, a 7-member project team used a variety of methods to gather information from a wide range of sources and stakeholders. Information gathering activities took place over the period of November 1, 2017 through September 30, 2018 and included multiple components as outlined below:

- Reviewing the literature and creating an online project library containing 80+ journal articles, government reports, presentations, articles published in the trade press and newspapers, and other source materials.

- Collecting and reviewing relevant federal and state statutes and regulations related to hospital discharge planning including Section 1802 of the Social Security Act; federal Anti-Kickback Statute [42 U.S.C. § 1320a-7b(b)]; CMS Conditions of Participation in the Medicare program; the New York Codes, Rules, and Regulations Title 10, Part 405.9; New York State Caregiver Advise, Record, and Enable (CARE) Act of 2014; and Improving Medicare Post-Acute Care Transformation Act of 2014 and related proposed and final rules and regulations (e.g., the Final Rule, October 24, 2016).

- Scanning quality measures available to the public on the Internet including Medicare.gov Nursing Home Compare and Home Health Compare; New York State Department of Health's NYSHealth Profiles for nursing homes and home care agencies and its Nursing Home Quality Initiative web pages, ProPublica's Nursing Home Inspect Tool, the Long Term Community Care Coalition web site, and web sites operated by nine other states that provide information for consumers seeking PAC providers including California, Minnesota, Ohio, Rhode Island, Massachusetts, Florida, Arizona, Wisconsin, and Pennsylvania.

- Meeting and conducting phone interviews with a total of 26 researchers, subject matter experts, innovators, advisors, and other key stakeholders from research universities, state government, advocacy organizations, provider organizations, quality improvement organizations, and elsewhere. Topics covered included perspectives on the discharge planning process, PAC decision-making, constraints on patient choice, uneven quality of PAC providers, publicly available quality information and gaps, Nursing Home Compare, innovative models and tools, opportunities for improvement, legal and regulatory barriers, potential policy levers, and emerging PAC networks, among others.

- Convening small group meetings and phone interviews with a combined total of 17 former patients and family caregivers who had experienced a hospitalization followed by a post-acute stay in a SNF. Topics covered included: what choices were presented for PAC, what options the patients and family caregivers considered, how the information was presented and discussed, the reasons that the patients and family caregivers chose a facility, what mattered most to them when making a choice, and what information would have been helpful.

- Holding 90-minute, in-person meetings with leaders and frontline staff at eight hospitals in the greater New York metropolitan area. Topics covered included: how

patients are evaluated for PAC, how patients and families are involved in discharge planning, what pressures staff face during discharge planning, what information is provided to patients and families to help choose a facility, whether staff use the CMS Compare or New York State Health Profiles websites, whether patients and families ask for recommendations, thoughts on federal and state regulations, whether the hospitals have a preferred provider network and how it impacts quality of care, and ideas on how to improve the discharge planning process and communication with patients and families about SNF selection.

- Conducting semi-structured phone interviews with administrators at 5 SNFs in the New York metropolitan area. Topics covered included: how patients are evaluated for admission, what factors limit the choices that patients and families have, whether the SNF participates in a preferred provider network and what kinds of discharge planning and quality improvement processes they have in place, how transitions can be improved, what patients and families ask about during a visit, and how patient and family choice could be improved.

- Scanning the literature and contacting experts to discuss innovative decision-support tools and best practices, staffing models, the use of social media and other websites to fill gaps in information that patients and family caregivers find meaningful, and new developments in hospital/PAC relationships that could help promote informed, value-based choices about PAC.

We then summarized and synthesized the results to identify common themes, barriers, and potential opportunities for improvement and produced a series of reports on our findings including this initial one. Additional findings and potential levers and strategies were considered at a stakeholder forum sponsored by the United Hospital Fund and New York State Health Foundation on November 7, 2018.

Appendix B. Statewide Performance Results on SNF and Certified HHA Quality Measures

Table B1. Skilled Nursing Facilities: Comparison of Selected Characteristics and Performance Rates That Can Be Found on CMS Nursing Home (NH) Compare and New York State Health Profiles (NYS HP)

Characteristic/Indicator	U.S. Mean[1]	NYS Mean[1]	NYS Range[2]	On NH Compare	On NYS HP
Certified beds				X	
Occupancy rate					X
Ownership Status (proprietary, not-for-profit public)				X	X
Staffing					
Average residents per day	86.6	168.1		X	
Total no. of licensed nurse staff hours/resident/day	1.55	1.48		X	
RN hours/resident/day	0.67	0.67		X	
PN/LVN hours/resident/day	0.88	0.82		X	
CNA hours/resident/day	2.3	2.22		X	
PT staff hours/resident/day	0.12	0.13		X	
Short-Stay Quality Measures					
% who improved ability to move around on their own	67.9%	69.7%	6.6-100%	X	X
% re-hospitalized after a nursing home admission	22.4%	20.3%	3.4-35.4%	X	X
% who have had an outpatient ED visit	12.3%	9.9%	0-26.9%	X	X
% successfully discharged to the community	56.4%	54.8%	0-86.3%	X	X
% who self-report moderate to severe pain	13.0%	8.9%	0-41%	X	X
% with new or worsened pressure ulcers	0.9%	0.8%	0-35.2%	X	X
% who needed/got flu shot for the current season	81.6%	83.0%	20-100%	X	X
% who needed/got vaccine to prevent pneumonia	83.3%	81.0%	6.7-100%	X	X
% who got anti-psychotic medication for the first time	1.9%	1.6%	0-15%	X	X
Long-Stay Quality Measures					
% whose need for help with daily activities increased	15.0%	13.6%	0-34.5%	X	X
% reporting moderate to severe pain	5.6%	3.5%	0-19.1%	X	X
% high risk residents with pressure ulcers	5.6%	6.9%	0-27.4%	X	X
% who lost too much weight	7.0%	6.4%	0-19.5%	X	X
% low-risk residents who lose bowel or bladder control	48.1%	52.3%	0-97.1%	X	X
% who had a catheter inserted and left in their bladder	1.8%	1.4%	0-6.3%	X	X
% with urinary tract infection	3.2%	2.7%	0-15.6%	X	X
% with depressive symptoms	4.7%	6.5%	0-90%	X	X
% who were physically restrained	0.4%	0.6%	0-18.5%	X	X
% experiencing one or more falls with a major injury	3.4%	2.8%	0-9.5%	X	X
% given seasonal influenza vaccine	95.1%	96.8%	70.9-100%	X	X
% given pneumococcal vaccine	94.0%	94.9%	44.7-100%	X	X
% given anti-psychotic medication	15.2%	12.0%	N/A	X	
% whose ability to move independently worsens	18.3%	16.5%	0-41.6%	X	X
% who received an anti-anxiety or hypnotic medication	22.1%	14.8%	0-58.8%	X	X

N/A = Not available.
Sources: 1 CMS Nursing Home Compare; 2 New York State Department of Health New York State Nursing Home Profiles (both as of 10/12/2018). United Hospital Fund analysis, 2018.

Table B2. Certified Home Health Agencies: Comparison of Performance Rates That Can Be Found on CMS Nursing Home (NH) Compare and New York State Health Profiles (NYS HP)

Indicator	U.S. Mean[1]	NYS Mean[1]	NYS Range[2]	On NH Compare	On NYS HP
Managing Daily Activities					
Patients got better at bathing	76.6%	73.7%	36.7-98.6%	X	X
Patients got better at getting in and out of bed	72.3%	69.9%	37.3-90.9%	X	X
Patients got better at walking or moving around	74.1%	73.0%	31.5-100%	X	X
Managing Pain and Treating Symptoms					
Patients had less pain when moving around	77.2%	76.7%	29.1-100%	X	X
Patients' breathing improved	76.2%	78.6%	33.2-100%	X	X
Patients' wounds improved or healed after an operation	90.9%	90.4%	52.7-99.9%	X	X
Preventing Harm					
Home health team began their patients' care in a timely manner	93.9%	94.9%	69.9-100%	X	X
Home health team taught patients (or caregivers) about their drugs	98.0%	97.4%	23.4-100%	X	X
Patients got better at taking their drugs correctly by mouth	64.6%	62.8%	28.2-89.3%	X	X
Home health team checked patients' risk of falling	99.5%	99.5%	80-100%	X	X
Home health team checked patients for depression	97.8%	97.5%	28.1-100%	X	X
Home health team made sure that their patients have received a flu shot for the current season	77.8%	77.6%	37.5-100%	X	X
Home health team made sure that their patients have received a pneumococcal vaccine	80.9%	72.9%	26.3-100%	X	X
For patients with diabetes, home health team got doctor's orders, gave foot care, and taught patients about foot care	97.4%	98.2%	24.1-100%	X	X
Preventing Unplanned Hospital Care					
Patients had to be admitted to the hospital	15.8%	16.2%	0.1-22.8%	X	X
Patients needed any urgent, unplanned care in the hospital emergency room - without being admitted to the hospital	12.9%	10.7%	4.1-20.4%	X	X
Patient Survey/Patient Satisfaction					
Home health team gave care in a professional way	88.0%	84.0%	0-97%	X	X
Home health team communicated well with patients	85.0%	81.0%	49-94%	X	X
Home health team discussed medicines, pain, and home safety with patients	83.0%	80.0%	49-93%	X	X
Patients rating of overall care from home health agency	84.0%	78.0%	0-95%	X	X
Patients would recommend the home health agency to friends and family	78.0%	72.0%	0-95%	X	X

Notes: Data are for the 12-month period of 10/2016 to 9/2017 except for patient satisfaction measures, which are reported for 1/2017 to 12/2017.

Sources: 1 CMS Home Health Compare; 2 New York State Department of Health New York State Home Care Agency Profiles. United Hospital Fund analysis, 2018.

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