DIFFICULT DECISIONS

Pathways to Progress on Difficult Decisions in Post-Acute Care

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March 2019

United Hospital Fund

UHF works to build a more effective health care system for every New Yorker. An independent, nonprofit organization, we analyze public policy to inform decision-makers, find common ground among diverse stakeholders, and develop and support innovative programs that improve the quality, accessibility, affordability, and experience of patient care. To learn more, visit www.uhfnyc.org or follow us on Twitter at @UnitedHospFund.

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Introduction

Each year, over 8 million patients in U.S. hospitals, including some 300,000 New Yorkers, face a decision soon after admission about where to receive post-acute care (PAC).[1,2] Yet many patients and families may not be aware of how much could be riding on that decision, or of the benefits, risks, and costs that various PAC options might involve. Too often, patients and families must make these difficult decisions without the kind of assistance that could help them identify options more likely to support recovery—and help them avoid increased risk of declining health or loss of independence, and associated financial burdens.[3,4]

While decisions about PAC are pending, dedicated hospital care teams and discharge planning staff work behind the scenes to quickly arrange safe and appropriate discharge plans for patients.[5] However, despite staff efforts to smooth the discharge process, systemwide problems persist. The unintended consequences of regulation, fragmented care settings and payment systems, unclear accountability, and a lack of evidence-based guidelines and other information gaps have all played a role in crowding out support for careful assessment of PAC options.

What opportunities exist for addressing these challenges? What will be the best and most practical ways to close communication gaps, support the selection of higher-quality PAC providers, and minimize the risk of adverse outcomes? To help answer these questions and others related to improving PAC decision-making during hospital discharge planning, especially when facility-based care is needed, the United Hospital Fund (UHF) conducted a multifaceted project supported by the New York State Health Foundation and produced a series of reports. This fourth and final installment in the series recaps key project findings and highlights practices, innovations, and policy levers that map out pathways to progress.

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The **Difficult Decisions** series examines challenges to informed decision-making about post-acute care after hospital stays for major surgery, serious illness, or injury. 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. Previous reports—on the many factors that make informed decision-making about post-acute care so challenging; on the experiences of patients, families, and caregivers; and on the experiences of health care providers—can be found at https://uhfnyc.org/initiatives/post-acute-care/.

The Context for PAC Decision-Making

As part of the yearlong "Difficult Decisions" project, UHF conducted an in-depth review of the literature, regulations, and publicly available quality information related to PAC; held discussions with patients, family caregivers, health care providers, and other subject matter and policy experts; searched for promising approaches and innovations; and convened a stakeholder forum to seek broader perspectives.[i] The following sections summarize key findings about the environment of PAC and on-the-ground perspectives about decision-making during discharge planning when post-hospital care is needed.

The demand for PAC is growing. Several changes in health care and population trends mean the demand for PAC will likely rise further: shorter hospital stays, the continued shift of care to home and other lower-intensity settings, more people living into their 90s and beyond with chronic conditions, the aging of New York's baby boomers, and cost containment pressures.

> ### DEFINING POST-ACUTE CARE
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> According to the Centers for Medicare & Medicaid Services (CMS), 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 stakes are high because patients needing PAC are vulnerable and the quality of PAC is uneven. Patients who need PAC are among the sickest and most vulnerable in our health care system; for many of them, a PAC choice can mean very different outcomes: full recovery, cycling in and out of health care facilities, or becoming a nursing home resident. While many PAC providers in New York State deliver consistently excellent care, others do not.[ii] Patients who receive care from lower-quality providers are at greater risk of experiencing complications, rehospitalizations, and worse outcomes, which in turn contribute to higher costs of care.[6]

Patients don't know what they don't know. While most patients and families know or have heard about nursing homes or home care agencies in their communities, they are less familiar with the full range of available PAC settings,[iii] what rehabilitation and skilled nursing services entail, what their health insurance may cover for PAC, or which providers are in their health plan network. A host of factors can constrain PAC choices, which patients and families may not even realize—for example, a need for specialized

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i For a detailed description of the methods used to conduct this study, see Rogut L and Kothari P. November 2018. *Difficult Decisions About Post-Acute Care and Why They Matter*. Pages 21-22.

ii For example, rehospitalization rates in New York skilled nursing facilities ranged from 3% to 36% in 2017, and from 0% to 23% for certified home health agencies. For additional examples of variation in PAC quality in New York State, see Rogut L and Kothari P. November 2018. *Difficult Decisions About Post-Acute Care and Why They Matter.* Pages 14-16.

iii For a comprehensive listing of home and community-based options in New York, see LeadingAge New York, https://www.leadingageny.org/linkservid/CDF5A2F4-9DC2-1EBC-35863EAA8BA1FB9E/showMeta/0/.

services or costly drugs, physical or safety barriers in the home environment, lack of sufficient social support, insurance coverage limits, capacity of local PAC providers, and more.

Discharge planning for PAC is complex and time-sensitive.[7] It can take multiple members of a hospital care team and input from other specialists to develop and finalize a safe plan during a period when a patient's medical condition is still changing. Length of stay and cost pressures can lead to rushed processes that everyone involved senses and that can push patients and family caregivers, who often feel unprepared and overwhelmed, to make rapid decisions.[8,9]

Decision-making can pose daunting challenges for patients and families. Researching PAC options is time-consuming and complicated under the best circumstances. But during discharge planning, many patients are still quite ill, family caregivers are stretched and stressed, and time is of the essence. Trying to cull and make sense of quality information from multiple websites and site visits to skilled nursing facilities (SNFs) can overwhelm even the savviest health care consumer. People with limited literacy, numeracy, research skills, or English proficiency—and those with lack of access to or familiarity with the Internet—are especially disadvantaged.[10]

Hospital staff involvement is variable and sometimes falls short. There can be a disconnect between hospital staff efforts during discharge planning and how patients and their families experience them. In the course of this study, we found that staff interactions with patients and caregivers did not always keep them apprised of the steps in the discharge planning process or help facilitate the best possible match between care needs and PAC environment.[11] Instead, the patients and caregivers we interviewed were told that discharge was imminent, and most were either unaware that they had a choice in PAC settings or were not actively engaged in decision-making.

Publicly available quality information has limitations. Most of the information about PAC that can be found on the Internet is not customizable or especially helpful for identifying and assessing which services or care settings would be most beneficial for an individual patient's situation or recovery. Some online information about providers is promotional in nature or doesn't meet standards for scientific validity or reliability, drawbacks that may not be apparent to users. Although government websites[iv] contain valid performance results on quality measures, those sites focus on technical aspects of quality rather than on dimensions that patients find meaningful.[12,13,14,15,16] Statistical data may not be helpful without other context to help patients see how they fit with their values and preferences. Instead, patients and families often seek and rely on word-of-mouth recommendations from friends, family, neighbors, health care professionals, and other patients. They also search for ratings and reviews on Google, Yelp, and Facebook.[17,18]

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iv For example, the CMS Nursing Home and Home Health Compare and New York State Health Profiles web pages for nursing homes and certified home health agencies.

Existing legal safeguards don't go far enough. Though they provide important protections to patients and caregivers during hospital discharge planning, current safeguards do not fully support careful assessment of PAC options. Most patients and caregivers want hospital staff to assist them with decisions about where to receive care. But narrow interpretation of federal law and regulations that prioritize "patient choice" and restrict hospitals from recommending specific PAC providers have further limited the decision support that patients and caregivers can receive.

Payment and care delivery reforms are underway. Quality metrics and payment incentives aimed at enhancing coordination or integration of acute and post-acute care are fostering the development of preferred PAC networks, in which hospitals select PAC organizations they plan to work more closely with to manage patient outcomes and costs. Such policies will undoubtedly affect the discharge planning process, including how decisions about PAC are made.

Given the relatively recent trend in preferred PAC networks, evidence about their impact is still evolving and very little is known about their effect on patients' and caregivers' experience with the discharge process. Networks could simplify decisions about PAC selection, maintaining patients' freedom of choice, yet preventing choice overload, which is known to constrain patients' ease and satisfaction with decision-making.[19] Hospitals would be able to distinguish a select number of PAC organizations from a broader list of facilities they provide to patients and caregivers.

On the other hand, the development of preferred networks might also lead to unintended consequences. Preferred networks may drive health systems to reduce readmissions that were necessary, as well as decrease appropriate use and PAC length of stay in SNF settings.[20] Preferred networks might also lead to increased disparities in PAC access for patients with complex medical needs, behavioral or substance abuse disorders.[21] More research will be needed to better understand how these networks are driving decisions.

The bottom line: As Robert E. Burke, MD, MS, FHM, an expert in this field, has summed it up, "Supporting high-quality PAC decision-making for patients requires far more than providing information."[22]

Pathways to Progress and Recommendations

Placing patients in the right setting with the right provider at the right time is essential to high-quality PAC but will remain out of reach until patient and caregiver needs are truly prioritized, and informed decision-making becomes an integral component of the discharge planning process. Without this shift, insufficient access to relevant information and helpful support will likely continue to lead to PAC choices that are based largely on location and not on quality of care.[23,24,25]

The good news is that there is no shortage of ideas about how to improve PAC decision support so that patients and family caregivers are more fully engaged, have better experiences during discharge planning, and are more satisfied and confident about their care decisions. During this project, we collected many promising ideas from the literature, experts in the field, patients and family caregivers, hospital staff involved in discharge planning, nursing home administrators, and participants in a stakeholder forum sponsored by UHF and the New York State Health Foundation.[v] We synthesized these ideas along with our own findings to provide a range of strategies for addressing the many challenges that will need to be tackled for progress to be made. These strategies for change are organized around six potential levers: engaging patients and families, improving discharge planning, bridging silos to create the conditions for informed decision-making, addressing regulatory and payment policy barriers, enhancing public information and transparency, and increasing public awareness.

1. Engaging Patients and Families in Discharge Planning for PAC

Discussions with patients and their families revealed that they had little sense of the efforts underway on their behalf during discharge planning—or of the factors that could hamper those efforts and limit their choices. To begin to bridge this disconnect and foster greater trust, collaboration, and timely communication, the following strategies and steps are offered for consideration by hospital leaders and staff involved in discharge planning.

- Apply a shared decision-making approach by introducing information about PAC choices, reviewing associated risks and benefits of options, eliciting patient and family preferences, self-assessment of degree of preparedness and needs, and supporting decision-making based on what matters most to them.[26] See Appendices A and B for additional information on engaging patients with a shared decision-making model.

- Bring relevant information to the bedside through closed-circuit television, videos, tablets, and apps that can help patients research their PAC options.

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v The Difficult Decisions about Post-Acute Care Stakeholder Forum was held on Nov. 7, 2018.

- Consider the role of information intermediaries or navigators who are specially trained to support those needing more help with decision-making[vi]—for example, frail patients; patients and families with low literacy, numeracy, or research skills, or with limited English proficiency; or those without access to or familiarity with the Internet.

- Add Medicare Star Ratings to the PAC provider lists given to patients and families during discharge planning and review that information with them. This should include the separate quality ratings for short-stay and long-stay residents that will become available on Nursing Home Compare in April 2019.[27]

- Give checklists to families to use for site visits, provide enough time for them to conduct visits, and close the loop by reviewing the results with them.

- For health systems that have a PAC network, review information with patients and families about which agencies and facilities are part of the network, how they were selected, and their recent performance results on quality measures, health inspections, and nurse staffing levels.

- Educate patients and families about what to expect from PAC services provided by a home health agency or SNF; to prevent misunderstanding, inform them about the level and frequency of services and the type of staff who will provide those services.

2. Improving the Discharge Planning Process

Discharge planning is a complex process with numerous opportunities for important steps or information to slip through the cracks.[vii] The following approaches and tools, some proven and some newer, could help hospitals improve discharge planning and access information more effectively.

- Apply the tools and techniques of quality improvement to map processes, analyze bottlenecks, pinpoint communication gaps, ensure that patients and caregivers are updated on the progress of discharge planning tasks, identify opportunities for streamlining workflows that clarify team member responsibilities, and assess effects on patient and family caregiver experiences.

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vi For a description of possible roles for information intermediaries in connecting individuals with information and providing decision support, see Agency for Health Care Research in Quality https://www.ahrq.gov/professionals/quality-patient-safety/talkingquality/create/support/limitations.html.

vii For a comprehensive analysis of the barriers to providing high-quality, consistent discharge planning in New York and options for addressing them, see NYSDOH, *Improving the Discharge Planning Process in New York State*, January 2016. NYSDOH does not require hospitals to use a comprehensive standardized assessment tool to identify a patient's post-discharge care needs. Current tools—the Patient Review Instrument and Preadmission Screen Resident Review have been recognized as providing insufficient information to construct a patient-centered discharge plan. See https://www.health.ny.gov/press/reports/docs/discharge_plan_brief.pdf, pages 4-5.

- Develop protocols to standardize discharge planning for patients with common conditions, such as acute myocardial infarction, chest pain, diabetes, congestive heart failure, gastrointestinal infection, or stroke.

- Expand the leadership role of hospitalists in discharge planning decisions and care coordination oversight.[28,29]

- Assess the feasibility and validity of new care management platforms that include risk stratification and decision support tools, such as Careport, naviHealth, Aidin, Profility, Repisodic and Remedy Partners. See Appendix C for additional information on new decision support tools.

- Identify and adopt validated health literacy resources developed to inform consumers about various aspects of PAC. Many of the decision support tools noted in Appendix C provide them.

- Collaborate with community-based organizations to strengthen and align in-home support services.[30]

- Harness new electronic community resource directories and referral platforms—such as NowPow, Healthify, or Aunt Bertha—or use NY Connects to link patients to long-term services and supports.

Making an informed decision about PAC requires a degree of professional expertise that most patients and families do not have – for example, knowing what type of care is more likely to lead to the best possible recovery, what various insurance plans cover, or how to interpret performance on quality measures and compare the quality of available providers. Hospital clinicians and discharge planners may be best positioned to help patients understand their care options, sort through the tradeoffs, and avoid the risks of choosing lower-quality PAC providers. To help staff assume this role, hospital and health system leaders could take several specific steps.

- Request a legal review to clarify that federal regulations permit staff to help patients find and interpret quality-related information from the CMS Compare websites or New York State Health Profiles.[31,32,33]

- Issue guidelines and offer training sessions so that staff understand the extent and limits of the information and support they can provide.

- Engage geriatricians and physiatrists who have trained in post-acute care to help care teams better understand the SNF environment and the role of a SNF in a patient's rehabilitation.[34]

- Increase hospital staff familiarity with publicly available data about PAC, including health inspections, staffing levels, and quality measures. Train designated staff to access, compare, and interpret PAC provider performance results on the CMS Compare and New York State Department of Health (NYSDOH) websites.

- Develop scripts that designated staff can use to discuss PAC options and review provider performance results with patients and family caregivers or designated representatives.

- Counsel hospital staff who participate in discharge planning on ways to provide information about PAC so that patients and families can process it without being overwhelmed.

3. Bridging Silos to Create the Conditions for Informed Decision-Making

Despite the promise of value-based reforms, how quickly they will take hold and how much shared accountability they will achieve across settings remains uncertain. In the meantime, intermediate steps that begin to connect care setting and payment silos could help create the conditions for informed decision-making and better patient and family experiences during discharge planning.

- Investing in comparative effectiveness research and prescriptive analytics to strengthen the evidence base for informing decisions about the most suitable mix of care options for individuals.

- Cross-training clinicians employed by hospitals, accountable care organizations, and PAC providers (e.g., through rotations) or creating opportunities for health system clinicians to work in both acute and post-acute settings.[35]

- Increasing clinician access to electronic health records across settings (e.g., through the eight regional health improvement organizations in New York).

- Examining how silos in payment for PAC (e.g., Medicare and Medicaid) and nursing home reimbursement rates can limit access to timely, comprehensive, and coordinated care for sick and vulnerable patients.

- Considering how payment models or other policy levers (e.g., risk-adjusted rate enhancements, public reporting, or pay-for-performance models) might be used to expand access, support facilities that care for the most complex or difficult-to-place patients, or incentivize better experiences for patients and families.[viii]

4. Addressing Regulatory and Payment Policy Barriers

Regulation has had a sizeable influence on discharge planning in both facilitating and limiting the decision support that hospital staff can provide to patients and caregivers.

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viii A recent study of how individual hospitals and SNF administrators strategize transfers of older patients warned that increased hospital-SNF integration could lead to greater disparities in quality of care for patients with complex medical needs. See Shield R, Winblad U, McHugh J, Gadbois E, and Tyler D. 2018. Choosing the Best and Scrambling for the Rest: Hospital-Nursing Home Relationships and Admissions to Post-Acute Care, *Journal of Applied Gerontology*. Epub ahead of print. doi: 10.1177/0733464817752084

Current regulations and the policies underpinning them need to be realigned to improve discharge planning for PAC, prioritize patients and families' needs, improve their discharge planning experience, and produce more comprehensive and coordinated care. Several suggestions emerged during UHF's discussions with providers that might help support this shift.

- Reassessing the three-day hospital stay required before Medicare will cover PAC in a SNF or including time spent in the hospital under observation status for meeting length-of-stay requirements.

- Aligning differences in federal and state discharge planning regulations—e.g., about what information must be provided to patients or their representatives.[ix]

- Consider eliminating the required use of the Patient Review Instrument (PRI), which hospital and nursing home staff members view as outdated.

- Addressing the lengthy process for determining Medicaid eligibility, which can affect patient access to SNF care (e.g., expediting the determination process or presuming eligibility).[x]

- Addressing the underlying causes of delays in insurance authorization for PAC services, which not only increase length of stay but can lead to patient and caregiver dissatisfaction when the discharge plan is stalled.

- Monitoring the impact of preferred PAC networks on the quality of PAC providers patients are discharged to, as well as on patients' experience of discharge planning, and on the quality of care coordination and continuity.[xi]

Federal discharge planning regulations have not been substantially revised in over 20 years.[36] A window of opportunity exists through November 2019 as CMS considers policy issues related to the IMPACT Act's proposed revisions to discharge planning requirements for hospitals.[37] Those pending regulatory changes 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 patients' goals of care and treatment preferences.[38] Their enactment could be a boon to patients and caregivers and could help begin to make informed decisions for PAC a reality.

ix NYSDOH has already considered this strategy and is waiting for CMS to issue a final rule on its proposed changes. See NYSDOH, *Improving the Discharge Planning Process in New York State*, January 2016, p. 18-19.

x For more information about these strategies, see NYSDOH, *Improving the Discharge Planning Process in New York State*, January 2016, p. 12-13.

xi For example, Medicare Advantage's adoption of narrow PAC networks seems to be driving patients to higher quality PAC providers, and there is some evidence to suggest that hospitals' preferred networks are also having a positive effect of lowering hospital readmission rates. See Jung H-Y, Li Q, Rahman M, and Mor V. 2018. Medicare Advantage Enrollees' Use of Nursing Homes: Trends and Nursing Home Characteristics. *The American Journal of Managed Care* 24(8): e249-e256.

5. Enhancing Public Information and Transparency

The Medicare Payment Advisory Commission (MedPAC) has shown that the availability of provider-specific performance data has not increased utilization of higher-quality PAC providers by Medicare beneficiaries.[39] Numerous studies document low uptake of government websites that display provider performance results, and consumers remain uncertain about where to find meaningful and reliable quality information they can trust.[40,41,42] To make online research easier and more relevant to the decisions patients and family caregivers need to make, several steps could be taken to ensure that they can more easily find and benefit from reviewing quality information that is thoroughly sourced and clearly presented.

- CMS should continue to improve Nursing Home Compare and promote its use by the public for assessing and choosing a PAC provider. Opportunities include:

  - Distinguishing performance results for short-term rehab[xii] and long-term stay and developing report cards comprised of a smaller number of high-priority outcome and experience measures that consumers value.[xiii]

  - Using principles of effective web design and other content that patients and families find meaningful: intuitive structure, size and content hierarchy, accessibility, mobile-friendly pages, integration of additional resources or references for users, multiple search functions and filters to ease navigation, and decision aids to support common decisions about PAC.

  - Providing information in languages other than English.

- CMS or NYSDOH could require PAC facilities to begin standardized reporting of patient experience—for example, through implementation of the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) for Nursing Homes.[xiv,43]

- CMS could require Medicare Advantage Plans to be more transparent about the quality of SNFs in their networks when beneficiaries make their enrollment decisions.[44]

- Exploring the potential for consumer assistance programs to provide information and support to patients and families—e.g., the Independent Consumer Advocacy Network, or the network of local offices for the aging in New York State.

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xii For example, in 2018, *U.S. News and World Report* introduced new short-stay rehabilitation ratings on its Nursing Home Finder website. See http://static.usnews.com/documents/health/nursing-homes/BNH_2018-19_Methodology.pdf, accessed Dec. 24, 2018.

xiii MedPAC discusses an approach using outcome measures such as hospital readmission and discharge to the community in MedPAC Report to the Congress: Medicare and the Health Care Delivery System. June 2018, p. 123-6.

xiv The CAHPS® Nursing Home Surveys include three standardized instruments designed to gather information on the experiences of adult nursing home residents and their family members. Each instrument is designed to meet a different need: Discharged Resident Survey (short-stay), Long-Stay Resident Survey (in-person structured interview) and Family Member Survey. These surveys can be used in monitoring programs designed to improve residents' experiences in nursing homes and can be a useful measurement tool for quality improvement.

In addition, NYSDOH could enhance the Nursing Home Profiles website by adopting relevant best practices from other state sites, such as California's CalQualityCare.org or the other state sites analyzed in Appendix D:

- Enabling the ability to compare facilities and their star ratings together on a map to make filtering by location and quality easier.

- Displaying provider-specific performance results separately for short- and long-stay patients.

- Collecting PAC patient experience data (e.g., through CAHPS) and adding it to the Nursing Home profiles.

- Including more facility information that might be relevant to patients and families:

  o Languages spoken, policies (on pets, smoking, security, etc.), bed availability, specialty services, cost of a single room, and other out-of-pocket costs

  o Patient demographic data

  o Condition-specific outcomes

  o Structural quality indicators such as credentials of executives and clinical staff

  o Staffing data available on Nursing Home Compare, as well as temporary staff usage and turnover data available from New York's Nursing Home Quality Initiative

  o Performance results and ratings on short-stay, long-stay and family experience indicators

  o Options for adding or linking to sources of patient and caregiver comments, although bias remains an issue

- Adding an "advanced search" option that would help consumers filter options based on their priorities.

- Translating web pages into other languages for consumers not fluent in English.

- Adding links to the websites of PAC providers in New York or linking to an aggregator site.

In addition, SNFs and other PAC settings could be encouraged to make their websites and brochures more useful by describing what services are provided, what a typical day is like, and other structural or facility features of interest to patients and families.[45]

6. Increasing Public and Professional Awareness

Many people are not familiar with PAC services or provider types and have little sense of the limitations of their PAC insurance benefits or why provider quality is important to consider. The silos in our health system have also created knowledge barriers about PAC among clinicians.[46] To help boost awareness, key stakeholders such as state government, professional organizations, and community-based organizations could consider the following activities:

- Designing a campaign to spread awareness about PAC among New Yorkers—what it is and why it's important, what insurance covers and what its limits are, how to assess PAC quality and health plans' PAC provider networks, what to expect as a patient or caregiver, and how to appeal a discharge decision when a patient is hospitalized.

- Developing a continuing education program for community-based clinicians (e.g., primary care providers and social workers) that focuses on the types of PAC services and populations served, the range of providers and programs available in New York State, insurance coverage and its limits, and how to find and interpret comparative performance results on the CMS Compare and NYSDOH Health Profiles websites.[xv]

- Encouraging community-based organizations and primary care providers to initiate conversations about PAC with patients or clients who are planning to have surgery or who have had repeated emergency room visits and are at risk of hospitalization, so that more patients and families understand that they may face a decision about PAC and what they would then need to consider.

xv Poor understanding of home health care services among hospital clinicians and primary care providers has been found to contribute to patient dissatisfaction with home health care. See Jones CD and Burke RE. May 2018. Annals for Hospitalists Inpatient Notes: Getting Past the "Black Box"—Opportunities for Hospitals to Improve Postacute Care Transitions. *Annals of Internal Medicine* 168(10): HO2-HO3.

Conclusion

Decision-making about PAC can be a risky proposition, as UHF's *Difficult Decisions* series demonstrates. Communication gaps, regulatory barriers, and efficiency pressures can disadvantage patients and families and impede their ability to make informed decisions about where to receive the best possible care. An emphasis on "patient choice" among policymakers and hospital staff has placed the burden of research and decision-making on patients and caregivers, leaving many in the dark about their options.

From patients' and families' perspectives, progress will require more timely communication about PAC options, designating a trusted care team member who can evaluate options together with them, tailoring information to a patient's needs and family circumstances, respecting their priorities, and easing the burden and rush of comparison-shopping for a provider. But achieving these aims will also require addressing broader impediments to informed decision-making in our health care system.

Tackling the complex and multifaceted barriers UHF's analysis has identified will take sustained action on multiple levels—individual, community, system, and policy. Fostering closer alignment and collaboration among patients, families, hospital staff, PAC providers, community-based organizations, payers, and policymakers will not be easy, but doing so is central to better serving patients and families and improving outcomes. Proposed changes to discharge planning regulations could serve as the impetus for more concerted actions to advance informed decision-making if CMS enacts them in 2019. Even so, additional resources to support staffing model changes, clinician training, information technology, decision support, and process improvement will also be needed to bridge silos across care settings. More must be done to ensure that all hospitalized patients in need of PAC, together with their family members, understand the full range of options that could meet their needs and are equipped to make informed decisions when choosing a provider. The principles of patient autonomy and provider accountability demand nothing less.

Appendix A. Shared Decision-Making Model to Engage Patients in PAC Planning

The planning of PAC entails decisions that hinge on a large number of factors—e.g., service needs and availability, insurance coverage, and patient preferences and values. Such a complex process requires the care team to focus patients and caregivers to review information and understand how these choices relate to their health condition and values, broad questions they may not have considered before. Yet our findings suggest that discharge preparation and planning remain for the most part, centered on providers. We note that evidence-based resources developed in the past two decades to support those activities, did not generally involve formal and explicit patient or caregiver input regarding their own assessments of risk and degree of preparedness, and most did not elicit or aim to clarify how patients' values and preferences might guide decisions. In this section we describe findings regarding decision support innovations, as well as promising instruments to prioritize patients' assessments of their own needs.

A shared decision-making model that engages the patient/caregiver and staff in the context of planning for PAC offers great promise to address these issues, and as a strategy to improve the experience and the outcome of the decision. This model has three essential elements:

1. shared information about the patients' PAC needs and based on those, an assessment of the degree of preparedness and preferences of patients and caregivers

2. decision support tools to help narrow down choice to an optimal number of options for PAC services appropriate to the needs and preferences of patients

3. individual guidance to clarify values and support patients and caregivers in making complex trade-offs

Shared decision making has been successfully adopted in health care, to guide patients' decisions about treatment options based on their preferences (e.g., surgery v. watchful waiting for patients with early-stage prostate cancer), but our review revealed that this model has not been used much and is just beginning to be employed in the context of PAC discharge planning. As a framework it could have the power to address several gaps noted over the course of this Difficult Decisions project.[47]

Appendix B. Opportunities to Engage Patients in the Assessment of PAC Risks, Needs, and Preparedness

Assessing patient risks and PAC needs is an essential component of the discharge preparation and decision process. Yet, in most cases, assessments are done primarily through the care team's lens, where risks and needs are determined using biometric and clinical data. A key element of information, risks that might concern patients and caregivers, is thus often neglected.[xvi] This can lead to the development of a discharge plan that is not fully tailored to the patient's unique situation and preferences.

For the most part, the patient-level information used in decision support tools we reviewed does not include patient-reported data. Yet we did identify several validated questionnaires (Table 1, on the following page) that address preparation and planning framed through the perspective of patients and caregivers. These hold promise for broader adoption and even inclusion in more sophisticated decision support tools. For example: questionnaires used in care transition programs such as Better Outcomes for Older Americans Through Safe Transitions (BOOST) could be considered for adoption by care teams; PREPARED questionnaires capture specific domains of best practice discharge planning, from different stakeholders' perspectives;[48] the Readiness for Hospital Discharge Survey (RHDS) collects patient-reported information to predict post-discharge risk for future adverse outcomes.[49] Efficient approaches to adopt such questionnaires routinely for discharge decision-making by patients and care teams will need to be explored.

In summary, our findings suggest that PAC decision-making is still predominantly provider-focused, and that key information that can only be obtained by patients and caregivers regarding risks, degree of preparedness, and concerns could be prioritized and included in the decision-making process in a more standardized and explicit way. PAC decision-support tools are proliferating rapidly, and each tool offers specific advantages as well as limitations. We identified a unique opportunity for those tools to engage patients and caregivers with patient-reported data collected by validated questionnaires.

xvi Private Sector Hospital Discharge Tools: Sample of hospital discharge planning tools that strive to improve transitions to post-acute care and reduce readmissions.

Table 1: Patient and Caregiver PAC Needs and Readiness Assessment Questionnaires

Patient and Caregiver-Reported PAC Needs and Readiness Assessment Questionnaires	Questionnaire Domains
<u>BOOST</u>: Better Outcomes for Older Adults through Safe Transitions is a national initiative led by the Society of Hospital Medicine to improve the care of patients as they transition from hospital to home. The initiative led to the development of four major patient-reported questionnaires addressing various domains of PAC preparedness.	• General discharge preparedness assessment (GAP). • Patient Preparation to Address Situations (after discharge) Successfully (PASS). • Patient-centered discharge education tools; and a "teach back" assessment. • Care Transition Measure (CTM-15)
<u>PREPARED</u>: a set of five interlinked surveys developed by the iCAHE (International Centre for Allied Health Evidence), University of South Australia. Includes perspectives of different stakeholders: medical practitioners, residential care administrators, community service providers, and patients and caregivers.	• Prescriptions • Readiness to re-enter community • Education • Placement • Assurance of safety • Realistic expectations • Empowerment • Directed to appropriate services
<u>Readiness for hospital discharge (RHDS)</u> is a validated 21-item patient survey that assesses self-reported discharge readiness.	• Personal status • Knowledge • Perceived coping ability • Expected support

Sources: Graumlich JF, Novotny NL, and Aldag JC. 2008. Prepared for Discharge Scale. *J. Hosp. Med* 6:446-454. doi:10.1002/jhm.316. Weiss ME and Piacentine LB. December 2006. Psychometric Properties of the Readiness for Hospital Discharge Scale. *Journal of Nursing Measurement* 14(3): 163-80.

Appendix C. Decision Support Tools

A growing number of PAC decision-support tools are being developed to address the gap in patient engagement in the discharge planning process. Some are still in pilot or early evaluation phases, while others have been adopted in acute care settings in New York City. Our review is not meant to be comprehensive, but rather to provide insights on their nature and how they help streamline PAC options (Table 2).

Ideally, a decision support tool would allow patients to access customized information about their PAC options. The degree of customization and matching of patient to PAC setting will vary depending on the sophistication in the patient-level data used. For example, public reporting websites such as Nursing Home Compare typically provide population-based information that allow patients to compare various skilled nursing facilities based on several criteria. Patients and caregivers need to synthesize the information to their own circumstances and preferences, and that can be quite challenging. And the options identified may not be fully relevant. Through literature review, conversations with clinical staff and experts in post-acute care we identified several new tools that attempt to address these limitations by synthesizing vast amounts of patient- and provider-specific data with innovative analytics that can better match patients to a narrow, more specific group of options. The tools from naviHealth, Profility, Aidin, Repisodic, CarePort and Remedy Partners fall into this category. Some tools use local and time-sensitive data to narrow down the number of PAC options, such as bed availability and type of insurance accepted.

Table 2: PAC Decision Support Tools and Analytic Methods

Selected Tools	Methods to Simplify PAC Decision Options
CMS Nursing Home Compare Star System	Ranking methodology based on expert input
CarePort naviHealth Aidin Profility Repisodic	Matching algorithms based on patient- and PAC provider-level data
Nursing Home Compare Plus	Matching algorithms based on patient preferences
Remedy Partners	Matching algorithms based on patient-derived assessment of degree of preparedness

Note: Remedy Partners holds a contract for program administration, data analytics, financing, and risk pooling under the CMS Bundled Payments for Care Improvement Initiative (BPCI).

Other tools leverage patient level data that vary in degree of comprehensiveness—for example, patient demographics, biometrics, outcomes, patient-reported information. Some tools also use historical performance data to match patients with PAC providers and maximize the likelihood that the outcomes expected are achieved.

Nursing Home Compare Plus is a decision aid that attempts to include patient preferences into the matching process.[50] The tool uses publicly available data on Nursing Home Compare and guides patients to identify and rate PAC characteristics based on the degree with which each criterion matters to them. It then creates a personalized ranking of providers. However, the criteria available for patients to prioritize have *also* been defined by health care professionals—for example, rates of hospital readmission or pressure ulcers. Ideally, matching would include additional criteria that matter to patients—for example, level of physical or social function, independence, and other personal values.

All these decision support tools typically produce a list of PAC options for patients and caregivers to review. The more specific the matching, the more effective the tool is in informing decisions. The tools are typically part of a broader set of resources that provide various types of additional information about the PAC options presented, such as virtual video tours or photos of the facility. Some resources also include educational materials that explain PAC options and aim to increase health literacy given the complexity of PAC and the evidence that it is poorly understood. All those resources are key to support the decision-making process.

However, regardless of the degree of specificity that is reached by ranking or matching algorithms, the fact remains that PAC decisions are complex. They involve weighing numerous factors—and, even more importantly, the need for tradeoffs. Decision support tools can help narrow down these options considerably. Yet patients and family caregivers will still need support to talk through and clarify their priorities and values—and help in figuring out how to make tradeoffs based on them.

Appendix D. Publicly Available Quality Information on State Websites

Table 3. Comparison of Publicly Available Quality Information about SNFs on Selected State Websites

Website Feature/ Type of Information	% of Websites with Feature*	State Websites with Feature	NYS HP	CMS NHC
Website Display and Search Options				
Search Results Displayed on a Map	40%	CA, MN, NY, WI	✓	✓
Search by Services	20%	NY, OH	✓	
Search by Quality Measure	20%	MN, NY	✓	
Search Results Displayed on a Map with Quality Rating	10%	CA		
Displays Data Separately for Short- and Long-Stay Patients**	10%	CA		✓
Organizational and Resident Information				
Type of Payment Accepted (Medicare/Medicaid)	80%	AZ, CA, FL, NY, OH, PA, RI, WI	✓	✓
Number of Beds	60%	CA, FL, NY, PA, RI, WI	✓	✓
Ownership Type	40%	CA, NY, PA, WI	✓	✓
Occupancy Rate	30%	CA, FL, NY	✓	
Patient Demographics	10%	CA		
Languages Spoken	10%	FL		
Facility Policies (smoking, pets, DNR, etc.)	10%	OH		
Percentage of Beds in Single Rooms	10%	MN		
Religious Affiliation	10%	OH		
Staffing Data				
Hours of Direct Care Per Patient Per Day***	40%	CA, MN, OH, PA		✓
Staff Turnover/Retention	20%	CA, MN		
CMS Staff Star Rating	10%	RI		✓
Temporary Staff Usage***	10%	MN		
Average Nursing Wages	10%	CA		
Senior Staff Qualifications	10%	OH		
Inspections, Complaints, and Penalties				
Full Inspection Report or Link to Report	60%	AZ, CA, FL, MN, NY, PA	✓	✓
CMS Inspection Star Rating	50%	AZ, FL, MN, NY, RI	✓	✓
Fines/Enforcements	50%	AZ, CA, FL, MA, NY	✓	✓
Deficiencies/Citations	40%	CA, NY, OH, PA	✓	✓
Complaints	30%	CA, MA, NY	✓	✓
Quality and Satisfaction Information				
Custom Quality Measures or Composites	40%	AZ, FL, MA, NY	✓	
Resident Satisfaction Rating	30%	MN, OH, RI		
Family Satisfaction Rating	30%	MN, OH, RI		
CMS Quality Star Rating	20%	CA, RI		✓
CMS Individual Quality Measures	20%	CA, NY	✓	✓

NYS HP: New York State Nursing Home Profiles. CMS NHC: Centers for Medicare and Medicaid Nursing Home Compare. State websites reviewed are listed, with URLs, on the following page.

* N=10, not including CMS NHC. The 10 are listed on the following page.

** Short- and Long-Stay measures are displayed on HP but are grouped together under five new domains as of 8/31/2018.

Source: United Hospital Fund Analysis, 2019.

*** Not available on New York State Nursing Home Profiles (HP) but incorporated into Nursing Home Quality Initiative Annual Ranking (https://www.health.ny.gov/health_care/medicaid/redesign/nursing_home_quality_initiative.htm)

Websites reviewed as of January 6, 2019

Arizona Long-Term Care Provider: Search Form (https://hsapps.azdhs.gov/ls/sod/SearchProv.aspx?type=LTC)

CalQualityCare (http://www.calqualitycare.org/)

Florida Health Finder (http://www.floridahealthfinder.gov/CompareCare/SelectChoiceNH.aspx)

Massachusetts Nursing Home Performance Tool (https://eohhs.ehs.state.ma.us/nursehome/default.aspx)

Minnesota Nursing Home Report Card (http://nhreportcard.dhs.mn.gov/)

New York State Nursing Home Profiles (https://profiles.health.ny.gov/nursing_home)

Ohio Long-Term Care Consumer Guide (https://ltc.ohio.gov/default.aspx)

Pennsylvania Nursing Care Facility Locator Page (http://sais.health.pa.gov/commonpoc/nhLocatorie.asp)

Rhode Island Nursing Home Summary Report (pdf) (http://www.health.ri.gov/nursinghomes/about/quality/)

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