

Spotlight

# Family Caregiver Considerations for the Future of Hospital at Home Programs

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**Introduction**

The declaration of the COVID-19 public health emergency (PHE) accelerated an already burgeoning movement of health care into the home. An increasing number of health care systems are choosing to invest in home-based care in new and innovative ways, and consumers are using these services at unprecedented levels. The Hospital at Home (HaH) model shifts care into the home setting and delivers acute hospital-level care to eligible patients where they live instead of in a hospital. This shift in venue may be the way of the future, as it is unlikely that health care will revert to prepandemic patterns once the PHE ends. Although moving hospital care into the home may be associated with positive health outcomes and patient satisfaction, it raises concerns about support for and inclusion of family in these care models.<sup>1</sup>

All health care consumers are best served when their family caregivers are part of their care plans and supported by a health care team. Given the potential for increased dependence on caregivers, HaH programs should ensure that family caregivers are both included and supported. These individuals are largely left on their own to learn how to manage and perform medical and nursing tasks; however, many family caregivers feel they have no choice.<sup>2</sup> The recommendations included in this brief aim to ensure that HaH programs do the following:

- Seek family caregivers’ assent once patients consent to acute care at home.
- Do not expect caregivers to take on medical/nursing tasks but provide training for

caregivers who indicate they want those responsibilities.

- Set the patient and caregiver up for a successful transfer to postacute care.

Family caregivers are critical to HaH success, supplying vital observations, communications, and support for the patient, yet many current HaH programs neither explicitly account for the needs of family caregivers nor secure their assent. There is an overall lack of information regarding the expectations of family caregivers and how to access available support services in HaH programs. Further, few studies have assessed the impact of HaH on family caregivers. More inclusive and supportive policies for caregivers will allow HaH programs to truly meet the needs of both family caregivers and patients. In this publication, we present four Family Caregiver Considerations (see table) that HaH models can incorporate into policy and program design to best support these two groups.

**Diagnoses That May Be Eligible for Treatment Under Hospital at Home Model**

- |                            |   |
|----------------------------|---|
| • COPD                     | • UTIs                                    |
| • Pneumonia                | • Deep vein thrombosis/pulmonary embolism |
| • Congestive heart failure | • Early sepsis                            |
| • Asthma                   | • Seizure disorders                       |
| • COVID-19                 | • Gastrointestinal diseases               |
| • Hypertension             |   |

Family Caregiver Considerations	Elements
<b>Ensure choice, access, and equity</b>	<ul style="list-style-type: none"> <li>» Seek caregiver assent to guarantee voluntary participation</li> <li>» Ensure that there is equity in the patient populations served, including providing support services where income or language may pose a barrier to participation</li> </ul>
<b>Be clear and understandable to the patient and family caregiver</b>	<ul style="list-style-type: none"> <li>» Offer accurate and complete information about the HaH program</li> <li>» Clearly delineate all expectations of family caregiver</li> <li>» Specify any out-of-pocket costs</li> <li>» Give clear explanations of all services and how to access them</li> </ul>
<b>Recognize and support the family caregiver</b>	<ul style="list-style-type: none"> <li>» Do not expect caregivers to take on medical/nursing tasks</li> <li>» Ensure services and supports are available and provided to meet needs of both patient and family caregiver during HaH stay</li> <li>» Lead care coordination efforts so family caregiver is not responsible for coordinating care and services</li> <li>» Encourage family caregiver to share observations</li> <li>» Assist the patient and caregiver in setting up all necessary care and services to ensure a successful transition out of acute care</li> </ul>
<b>Allow for appropriate levels of research and learning</b>	<ul style="list-style-type: none"> <li>» Make data available to researchers</li> <li>» Conduct studies to evaluate impact of HaH programs on family caregivers and any issues related to access and equity</li> <li>» Share learnings across programs to coordinate larger efforts</li> </ul>

## Methods

The AARP Public Policy Institute (PPI) engaged ATI Advisory (ATI) to assist with research on the impact of HaH programs on family caregivers. This research included the following:

- Performing a landscape analysis of leading HaH programs across the country, focusing on a variety of parameters such as referral source, services provided to the patient and family caregiver, and outcomes data
- Reviewing existing published research on the impact and effectiveness of HaH models
- Conducting more than a dozen interviews with HaH program operators, stakeholders, and caregiver advocates to gain a more comprehensive perspective of this model and specific HaH programs
- Convening a PPI Innovation Roundtable to gather input from experts on HaH and family caregiving

Findings from this conducted research as well as feedback and ideas gathered during the interviews and roundtable event shaped the creation of the Family Caregiver Considerations presented in this policy brief.

## Background on Hospital at Home

### *History of Hospital at Home*

Researchers at the Johns Hopkins Schools of Medicine and Public Health first developed a HaH program in the United States in 1995.<sup>3</sup> Since then, dozens of health systems across the country have adopted and implemented HaH programs. Many current HaH programs have shown favorable outcomes, and research demonstrates that HaH models, when compared with traditional hospital care, are associated with improved patient safety, reduced mortality, better patient and family care experiences, and reduced costs.<sup>4</sup> Despite their presence in the United States for nearly

30 years and studies attesting to their positive impacts, HaH programs have not been widely available to consumers.

Prior to the PHE, the lack of a single reimbursement mechanism from the Centers for Medicare & Medicaid Services (CMS) and regulatory barriers hindered the growth of HaH in the United States.<sup>5</sup> The introduction of the CMS Acute Hospital Care at Home (AHCaH) waiver, detailed below, provided a single, hospital-level payment for care at home and eliminated regulatory barriers by waiving certain hospital conditions of participation related to nursing care.

**CMS Acute Hospital Care at Home Waiver Program**  
HaH programs entered a new stage with the onset of the COVID-19 pandemic. Amid

concerns about hospital capacity during the pandemic, CMS introduced regulatory flexibilities tied to the PHE that extended care outside the physical hospital setting. As part of this extension of care, in November 2020 CMS created the AHCaH waiver program,<sup>6</sup> which allowed qualifying hospitals (waivers were issued at the hospital level, not to whole hospital systems) to waive certain nursing care conditions of participation and offer acute inpatient care in the home. The AHCaH waiver serves eligible Medicare Fee-for-Service (FFS) and nonmanaged care Medicaid beneficiaries; participating hospitals received the same Medicare payment they would for an inpatient hospital stay. As of August 15, 2022, 248 hospitals across 111 health systems and 36 states were participating in this waiver program.<sup>7</sup>

**Program and Service Requirements for CMS Acute Hospital Care at Home Waiver<sup>8</sup>**

Program Requirements	Service Requirements
<ul style="list-style-type: none"> <li>• Patients must be admitted from an emergency room (ER) or inpatient hospital—no community admissions permitted</li> <li>• Participating hospitals must use specific selection criteria to determine if patient can be safely treated at home through this program</li> <li>• Participating hospitals must ensure that admitted patients require an acute inpatient admission and at least daily rounding by a medical team</li> <li>• Participating hospitals have discretion to determine which conditions to target and treat</li> <li>• Medical doctor/advanced practice provider and registered nurse (RN) are each required to visit once daily; RN or mobile integrated health paramedics must visit twice daily</li> </ul>	<p>Participating hospitals required to provide or contract for the following services:</p> <ul style="list-style-type: none"> <li>• Pharmacy</li> <li>• Infusion</li> <li>• Respiratory care, including oxygen delivery</li> <li>• Diagnostics (labs, radiology)</li> <li>• Monitoring with at least two sets of in-person patient vitals daily</li> <li>• Transportation</li> <li>• Food services including meal availability as needed by the patient</li> <li>• Durable medical equipment (such as hospital bed)</li> <li>• Physical, occupational, and speech therapy</li> <li>• Social work and care coordination</li> </ul> <p><i>Medicare inpatient payment policies and rates did not change, so participating hospitals are paid the same as if the care were provided in the traditional inpatient setting</i></p>

**Other (Non-CMS Waiver) Hospital at Home Programs**

Variation exists in HaH programs, particularly among payers and program design.<sup>9</sup> Although the CMS waiver program solely serves beneficiaries with Medicare FFS and nonmanaged care Medicaid, existing HaH programs also partner with other payers, such as Medicare Advantage, commercial, and managed Medicaid plans, for reimbursement. In addition, HaH programs that operate outside of the CMS waiver may admit patients from the community and therefore do not require patients to first be seen in the ER or admitted to the inpatient hospital setting. Some also operate as 30-day bundles, where hospitals are paid a fixed amount to cover services and fulfill needs for 30 days, extending care beyond the length of the acute hospitalization stay of 3 to 5 days and into the typical postdischarge period. This variation in design parameters affords an opportunity for evaluation, across programs, to determine the

optimal design for programs moving forward—particularly as CMS and Congress consider the future of HaH in Medicare and Medicaid.

**Role and Experience of Family Caregivers Within Hospital at Home Programs**

AARP PPI and ATI’s research and interviews revealed that many HaH programs have minimal, if any, formal expectations of family caregivers. The AHCaH waiver neither requires caregiver inclusion nor specifies what caregiver involvement in the care episode should or should not be. Most HaH programs do not require the presence of a family caregiver for a patient to be deemed eligible for a HaH stay. HaH programs report not requiring that the family caregiver perform any medical tasks or direct care, though some programs will offer training on basic tasks if the family caregiver is interested. If family caregivers are present, however, many HaH programs may require them to serve as a point of contact for the medical care team on the patient’s behalf.

**Key Traits of HaH (Non-CMS Waiver) Programs<sup>10</sup>**

<b>Payment sources</b>	Medicare Advantage, commercial, managed care Medicaid
<b>Referral sources</b>	Accept referrals from ER and/or inpatient hospital; referrals from community (clinic, urgent care, ambulatory practice) less common
<b>Length of care episode</b>	Some programs operate for length of typical hospital stay (~3–5 days), while others operate as 30-day episodes combining acute care and some postacute care
<b>Commonly provided services</b>	Visits by physicians and nurses (virtual/in person), vitals monitoring, medications, infusions, diagnostics, respiratory care, therapy, durable medical equipment, social work, meals; some provide home health aide (not included in CMS waiver services)
<b>Commonly treated conditions</b>	Pneumonia, congestive heart failure, chronic obstructive pulmonary disease (COPD), cellulitis, urinary tract infections (UTIs), asthma
<b>Requirement of family caregiver</b>	Not a common requirement, but some programs do require family caregiver to be present (none specify support services for the caregiver)
<b>Expectations of family caregiver</b>	If family caregivers are present, they are most often not expected to perform any medical tasks or direct care (can be trained on tasks if interested), but they may be asked to participate in some tasks, like serving as point of contact or stopping IV pump

Though not required to do so, family caregivers may be providing increased assistance to the patient with activities of daily living when the HaH care team is not present, and caregivers are likely handling household chores (e.g., cleaning, laundry). This assistance may already be part of the routine tasks that family caregivers take on, but these duties would not be necessary if the patient were to receive care in the hospital or ER. Moreover, patients' needs are often higher during the acute care episode, necessitating more intensive caregiver assistance. Our research revealed inconsistent availability of services to provide caregivers with respite and support as well as a lack of clear information about support and respite services and how caregivers could access them when they are available. For example, it was often unclear what triggers the provision of services, such as a home health aide or meal service, and their frequency.

Existing research does not focus on the impact of HaH on family caregivers, especially among programs within the United States. Though studies on HaH programs across the world have been published, findings on the experience and outcomes of family caregivers within these international programs are mixed. On one hand, multiple studies have shown that family caregivers in HaH programs had higher satisfaction levels<sup>11</sup> and lower stress levels<sup>12</sup> than those of comparison groups receiving care in the inpatient hospital setting. On the other hand, a 2007 study conducted in Canada discovered that family caregivers sustained added costs stemming from participation in the HaH program and expressed fears about its safety.<sup>13</sup> That said, HaH programs abroad may dramatically differ from those in the United States, given the variance in payment mechanisms and health care system structures, so this existing research may not be directly applicable to the US HaH experience. Nonetheless, as detailed in Family Caregiver Consideration 4, more research is necessary to gain a deeper understanding of the impact of HaH on family caregivers.

## Family Caregiver Considerations

The four Family Caregiver Considerations detailed below must be incorporated into HaH policy and program design by federal policy makers and HaH program operators. The inclusion of these considerations and supporting elements in HaH programs and policies will protect and support family caregivers and patients.

### Family Caregiver Consideration 1: Ensure Choice, Access, and Equity

#### Description:

Every HaH program should make clear that participation is voluntary for both patients and family caregivers and eliminate all barriers related to access and equity issues.

#### Key Elements:

- Request that family caregiver assent to guarantee voluntary participation (currently all HaH programs require only the patient's consent).
- Ensure equity in patient population served—provide support services where income or language may pose a barrier to participation.
- Train health care personnel to ensure they can provide culturally and linguistically appropriate care to diverse patient and caregiver populations.
- Ask patients and family caregivers about their specific needs regarding their home environment and engage them in solution-driven strategies to address these needs.
- HaH programs should use metrics and data to evaluate outcomes and the quality of care for patients and families from marginalized and disadvantaged backgrounds.

#### *Request caregiver assent to guarantee voluntary participation*

Voluntary participation in a HaH program should not end with the patient; it must extend to the family caregiver as well. Given the inevitable impact the decision to enroll in HaH will have on family caregivers, they must be active participants in this decision. Assent from family caregivers engages them in the decision-making process that occurs throughout

a HaH stay. HaH operators should have an intentional, focused conversation with the family caregiver to obtain assent; this dialogue should result in an agreement that formalizes this assent. Opportunity for a private, one-on-one conversation should be provided to family caregivers to discuss any questions or concerns that they may not feel comfortable raising in the patient's presence.

In the case that the patient consents but the family caregiver does not assent, HaH operators must carefully consider the options. Would this patient succeed in HaH without an assenting family caregiver? If yes, what extra support services must be in place (e.g., home health aide service for several hours each day) to ensure this patient's success? If this patient would not succeed without an assenting family caregiver, what information can the HaH program offer and what conversations must be had to ensure that all parties come to a final decision regarding participation? Though securing both consent and assent requires more upfront work by operators, aligning preferences and including both parties give operators a more informed understanding of how to design the patient's care plan to incorporate necessary services and address any expressed concerns.

### ***Eliminate barriers to serve diverse patients***

In addition to ensuring choice is granted to both patients and family caregivers, we recommend that HaH programs eliminate barriers related to ease of access to care. Community admissions allow more individuals to enter a HaH program, and though the requirement of an ER or inpatient admission (current requirement within the CMS waiver program) can act as a guardrail to ensure provision of appropriate hospital-level care, it may conversely act as a barrier to entry. Patients may be hesitant to enter an institutional setting; research shows that institutional distrust is higher among racial and ethnic minorities and populations of lower socioeconomic status.<sup>14</sup> Additionally, family caregivers may not have the time or flexibility to bring their care recipient to a hospital, which could be miles away. As such, guardrails

must be incorporated and leveraged to ensure safety and appropriateness when community admissions are used.

HaH programs must ensure that their patient population reflects the diversity of the communities they serve. One way to do this is by ensuring that HaH staff are representative of the communities who will constitute the patient population. To foster trust with patients and families in diverse communities, HaH programs should intentionally hire staff members who are racially, ethnically, and linguistically diverse. Further, all staff should be able to deliver culturally appropriate care to their patients, and HaH operators must ensure culturally attuned program design and processes. Care instructions should be provided in multiple languages and incorporate culturally tailored information for the diverse patients and family caregivers who participate in HaH programs.

As HaH programs continue to proliferate, operators must also ensure economic diversity, so these programs are not geared toward a specific population—especially one with higher income and socioeconomic status and residence in certain geographic areas. HaH programs must ensure that individuals across zip codes, including in subsidized housing, and individuals living in smaller homes have access to HaH if that is their preference. For example, HaH programs should provide Internet-enabled devices and secure network connections that allow for individuals, even those without Internet access, to participate in HaH. Additionally, it is imperative that support services and facilities be built in place in underserved and underresourced neighborhoods and communities. Many health care organizations have moved out of poor neighborhoods to capture market share, increasingly building new hospitals in more affluent areas. These organizations can positively affect health inequity by building in deprived areas, making health care available to underserved patient populations.

Addressing and eliminating barriers contribute to more equitable access to HaH across the

population, thus allowing more beneficiaries to reap the benefits of HaH programs.

### **Family Caregiver Consideration 2: Be Clear and Understandable to the Patient and Family Caregiver**

#### **Description:**

HaH programs must provide clear information to both patients and family caregivers about the program, expectations, and services.

#### **Key Elements:**

- Offer transparent portrayal of HaH program, including accurate and complete information about the program.
- Clearly delineate all expectations of family caregivers.
- Assess caregiver-related barriers that may affect HaH participation, including time constraints, caregiving burden, health literacy, employment issues, lack of psychosocial support, and financial burden.
- Specify any out-of-pocket costs.
- Provide clear explanations of all services and how to access them.

#### ***Offer transparent portrayal of HaH program, including associated pros and cons***

HaH program operators must be transparent in conversations with potential patients and family caregivers so individuals can be fully aware of the implications associated with HaH enrollment. Transparency can take the form of being proactive in conducting conversations with patients and family caregivers to inform them of the structure of the HaH program and how this model differs from a traditional inpatient stay. HaH programs can also explicitly highlight both the pros *and* the cons of the program. For example, HaH programs could include a list of the identified benefits and drawbacks of this program in HaH materials and incorporate these points into the eligibility assessment. Recognizing that HaH is not suited for every eligible patient and family caregiver and transparently portraying

the program will help manage patients' and caregivers' expectations. The goal is to not further overwhelm patients or family caregivers; it is to provide them with all the necessary information for them to make an informed decision that is most appropriate for their circumstances.

#### ***Clearly delineate all expectations of family caregivers***

HaH program operators must assess their model to identify any formal (e.g., serving as a designated point of contact) and informal (e.g., picking up medications at the pharmacy) tasks that the family caregiver may need to take on during a HaH stay. HaH operators should convey the possible range of expectations to the family caregiver early in the decision-making process, such as during the eligibility screening. To gauge the caregiver's ability to meet the identified expectations, operators should ask about the family caregiver's other responsibilities. If it appears that the family caregiver cannot meet these expectations, the HaH program must determine if there is a path forward, such as providing extra services to take on the tasks that the family caregiver cannot, or if enrollment in HaH is not appropriate in this situation.

#### ***Give clear explanations of all services and how to access them; specify any out-of-pocket costs***

Additionally, it is crucial that patients and family caregivers know what services are available in this model and how to access them. Unlike a hospital inpatient stay where many services happen automatically (e.g., staff deliver meals and wash soiled linens), HaH programs may require family caregivers to assertively vocalize any unmet needs. If caregivers do not, they may miss out on services that could benefit them and ease their care responsibilities during the stay. HaH programs should be explicit in listing the full package of services available within the program, including details such as the duration of the service, to whom the service can be provided (e.g., can meals be delivered to both

the patient and the family caregiver?), and any action needed to initiate a service. Similarly, these lists should include any services that are not available, to help align expectations of what is and is not possible under the model.

HaH programs should also specify, up front, any out-of-pocket costs to the patient and the caregiver. In many cases, caregivers provide financial support to their care recipient. For caregivers paying out of pocket to support care recipients, housing and medical costs make up the greatest share of their costs.<sup>15</sup> Caregivers and patients should have accurate expectations of the costs of a HaH stay.

### **Family Caregiver Consideration 3: Recognize and Support the Family Caregiver**

#### **Description:**

Family caregivers are critical to the success of HaH; as such, all programs must recognize and support these essential stakeholders by ensuring their needs are met and incorporating their voice and preferences.

#### **Key Elements:**

- Do not expect caregivers to take on medical/nursing tasks.
- Ensure services and supports are available and provided to meet the needs of both patient and family caregiver during HaH stay; assist in setting up all necessary care and services to ensure a successful transition out of acute care.
- Lead care coordination efforts so family caregiver is not responsible for coordinating care and services.
- Encourage family caregiver to share observations.

#### ***Do not expect caregivers to take on medical/nursing tasks***

Though caregiving roles and tasks may look different at home (e.g., increased laundry, assisting patient with increased care needs) than in the inpatient hospital setting (e.g., increased travel time, money spent on parking and cafeteria meals), they may still contribute to caregiver strain. Half of caregivers perform

medical/nursing tasks as part of their regular caregiving responsibilities, and they do not commonly receive any formal training on how to perform them.<sup>16</sup> Just as in the hospital, where there is no expectation that caregivers perform medical/nursing tasks for their care recipient, there should be no such expectation in HaH programs. Although some caregivers find these tasks difficult or emotionally challenging, other caregivers experience positive impacts in performing medical/nursing tasks for their care recipient. As such, HaH program should provide training and support on these tasks to those caregivers who want to take on those responsibilities during the care episode. HaH programs should not add complex tasks for which caregivers would not be responsible in the hospital; instead, they should support caregivers at the level of involvement they are willing to assume during the HaH stay.

#### ***Ensure services and supports are available and provided to meet needs of both patients and family caregivers during HaH stay; assist in setting up all necessary care and services to ensure a successful transition out of acute care***

The HaH episode of care should include any support services needed to ensure the family caregivers' responsibilities are no greater than they would be if the patient were in the hospital. Some caregivers will find that having their care recipients in the home causes less strain than having them receive care in the hospital (e.g., no parking costs, not having to manage travel to the hospital). Other caregivers, however, may find that the HaH stay leads to increased responsibilities for them or robs them of the respite care a hospital stay may have provided. To minimize any potential strain, HaH programs should offer supports, such as home care help, meal services, and even respite care, to caregivers and patients. Moreover, as noted in Family Caregiver Consideration 2, HaH operators should specify up front how caregivers and patients can access these services, the degree of frequency with which such services can be provided, and whether there are requirements for accessing them.

Patient care needs may vary when the patient reaches the end of the acute phase of care and treatment. Caregiving in the postacute phase may also differ because of residual effects that the patient may have from the acute phase. As such, family caregivers may require new resources and supports, such as connections to social services, help with ordering or locating durable medical equipment, or the provision of a home health aide for a limited time. Unlike a traditional inpatient stay, HaH programs can deliver critically needed support during the transition from the acute to the restorative postacute phase. They can connect patients and family caregivers to the services that they will need over the longer term as well as schedule follow-up care appointments.

During the episode of care, HaH programs have a unique opportunity to observe firsthand the patient's normal diet, cleanliness of the house, fall hazards, and more in the patient's home environment. By addressing any concerns there (e.g., providing nutrition education, resolving fall hazards), HaH operators may be able to prevent adverse health events, such as another ER or hospital visit, from occurring in the future. This benefit—one that traditional hospital stays cannot provide—is just another pivotal way that HaH can support patients and family caregivers and meet their needs.

***Lead care coordination efforts so family caregivers are not responsible for coordinating care and services***

HaH programs must provide care coordinators to coordinate medical care and support services across many providers during the episode. Family caregivers often play the role of quarterback for their care recipient, coordinating the various components of care. With the initiation of an HaH stay, family caregivers may be confronted with unfamiliar issues to navigate and additional services to organize. HaH program staff should take the lead on coordinating all forms of care, including the frequency and schedule of provider visits, to ensure there are no

unintended gaps in care or overlapping visit. HaH staff must maintain clear communication with patients and family caregivers to keep them abreast of any issues or changes. HaH programs must also manage the transition from the HaH stay to the postacute phase and support and connect patients and family caregivers with services to provide for a seamless care transition post-HaH.

***Encourage family caregivers to share observations***

HaH programs should invite family caregivers to share their observations and insights. Family caregivers play a critical role in a HaH stay because they are with the patient when the HaH care team is not present. The family caregiver might be the sole individual who can observe what happens during this timeframe, including the patient's sleep, bathroom use, and food intake. HaH programs should encourage family caregivers to share any observations—and any concerns—as a member of the care team. For example, family caregivers could contribute to care notes and documentation (with patient consent), thus inviting active collaboration between the patient and health care professionals. This task should not add strain to family caregivers; rather, it should empower them to speak up and contribute as desired.

#### **Family Caregiver Consideration 4: Allow for Appropriate Levels of Research and Learning**

##### **Description:**

Additional research to study and evaluate the impact of HaH programs, especially on family caregivers, will create opportunities for improvement and shared learning among programs.

##### **Key Elements:**

- Make data available to researchers.
- Conduct studies to evaluate impact of HaH programs on family caregivers and any issues related to access and equity.
- Share learnings across programs to coordinate larger efforts.

### ***Make data available to researchers***

As the number of HaH programs continues to increase, more research—particularly on the experiences and outcomes of family caregivers—must be conducted. The limited number of studies completed to date on HaH family caregivers have shown mixed results, and additional research could provide clarity.<sup>17</sup> To ensure that studies build on one another and that efforts are not unintentionally duplicated, future research should be coordinated among stakeholders in this field, such as the National Institutes of Health, Agency for Healthcare Research and Quality, CMS, and dedicated foundations.

Additionally, HaH data must be accessible to external researchers. CMS should add a modifier on all claims submitted for HaH-related services to allow researchers to compare utilization and performance metrics against claims without this modifier. The CMS waiver program currently tracks three metrics (see callout box) that are submitted to CMS on a regular basis.<sup>18</sup> However, these metrics do not fully capture the experience, outcomes, and impact of this program on

patients and family caregivers and should be expanded to encompass other data points. All metrics submitted to CMS should be converted into a publicly available data source (e.g., similar to the [Medicare Shared Savings Program ACO Public Use Files](#)) for researchers to analyze.

### ***Conduct studies to evaluate impact of HaH programs on family caregivers and any issues related to access and equity***

In addition to this need for more family caregiver-focused studies, the type of studies conducted should be expanded. Evaluative research studies could provide a more nuanced understanding of the benefits, risks, implications, and outcomes of HaH programs for patients and family caregivers. These types of studies can also be used to assess differences in benefits and outcomes across varied HaH program designs. Other types of studies, such as qualitative, mixed methods, and ethnographic research studies, should be conducted to gather valuable insights from a firsthand perspective and track the experience of a family caregiver throughout the span of the HaH program. These broader studies could help researchers better understand the expectations and experiences of family caregivers within HaH and generate more detailed comparisons between HaH and a traditional inpatient stay from the viewpoint of a family caregiver.

All studies should incorporate questions specific to the experience of the family caregiver and related to issues of access and equity. Although some HaH programs do implement satisfaction surveys, many only ask questions of the patients or ask a limited number of questions of the family caregiver.<sup>19</sup> Researchers should expand surveys to focus on the impact on and experience of family caregivers (see callout box for examples of questions). Furthermore, future HaH programs should design and conduct assessments to understand the tasks that family caregivers are responsible for during a HaH stay and to measure caregiver strain.

#### **Current Tracking and Reporting Requirements in CMS Waiver Program**

- Must track the following metrics and report them to hospital's Chief Medical Officer, Chief Nursing Officer, or Chief Executive Officer on weekly or monthly basis:
  - ❑ **Metric 1:** Unanticipated mortality during acute episode of care
  - ❑ **Metric 2:** Escalation rate (transfer back to traditional hospital setting during acute episode)
  - ❑ **Metric 3:** Volume of patients treated in program
- All metrics reported by volume of FFS Medicare, FFS Medicaid, and dual-eligible patients

### Examples of Questions to Assess the Impact on and Experience of Family Caregivers in HaH Programs

- Did having the family member or friend you care for enrolled in HaH make your role as a family caregiver easier, the same, or more difficult?
- What was your level of stress and strain between caring for your family member or friend in HaH and meeting other responsibilities in your life?
- How supported did you feel by the HaH care team during the HaH stay? How prepared do you feel to care for your family member or friend after the HaH stay as the result of services and/or trainings provided by the HaH care team?
- How would you describe your communication and interactions with the HaH care team? Did you feel involved, listened to, and treated with respect?
- Do you think the pros of HaH outweighed the cons?
- How likely would you be to prefer your family member or friend receive care in a HaH program instead of in a traditional inpatient hospital in the future?
- How likely would you be to recommend HaH to others?

Based on questions from the following sources:

Zarit Burden Interview Scale

Comparison of Stress Experienced by Family Members of Patients Treated in Hospital at Home with That of Those Receiving Traditional Acute Hospital Care (2008): <http://www.hospitalathome.org/files/HaH%20Caregiver%20Stress%20JAGS%2008.pdf>

TCARE Personal Caregiver Survey: <https://www.dshs.wa.gov/sites/default/files/ALISA/stakeholders/documents/Caregiver%20Personal%20Survey.docx>

HCAHPS Patients' Perspective of Care Survey: <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/HospitalQualityInits/HospitalHCAHPS>

All research tools should include questions related to demographic characteristics of the patient and family caregiver and be supplemented by qualitative research and data collection on both HaH and similar non-HaH patients. This approach not only will allow researchers to better understand the individuals served by HaH programs but also will help identify potential barriers to care—a first step in eliminating such barriers.

#### **Share learnings across programs to coordinate larger efforts**

Findings from additional research and studies must be shared across HaH programs to maximize the benefits of this model. The Hospital at Home Users Group, composed of HaH programs across North America working together to share resources and best practices and to expand HaH's reach, is a powerful

example of existing collaboration and a strong platform for sharing research findings. Future collaboration should incorporate the more nuanced supplementary research approaches (discussed above) and use these existing forums for collaboration. Forums like the Hospital at Home Users Group include program operators who may best be able to implement research findings on family caregiver experience, access, and equity into practical improvements to HaH programs.

#### **Conclusion**

Future HaH policy and program design must address the needs of family caregivers by incorporating the four Family Caregiver Considerations detailed in this policy brief. Given its expansion and advancement in the last two years—largely stemming from

the introduction of the CMS AHCaH waiver program and a greater shift of health care into the home—HaH is currently at a pivotal moment. However, the future of the CMS waiver program is unknown; it is tied to the PHE and is currently slated to sunset once the PHE expires. Efforts are in progress to sustain this program. For example, the bipartisan Hospital Inpatient Services Modernization Act aims to extend the existing waiver program for two years from the end of the PHE.<sup>20</sup> However, this legislation, as introduced, does not focus explicitly on family caregivers. Federal policy makers and HaH program operators must build on HaH's recent growth and advancements with an eye toward improvements that specifically

and intentionally meet family caregivers' needs. For HaH programs to succeed and fully benefit all parties involved, policy makers and HaH operators must acknowledge the crucial role that family caregivers have played—and will continue to play—in this care model.

### Acknowledgements

The authors express their gratitude to Tamryn Gray, PhD, RN, MPH, Harvard Medical School, for her contributions to the access and equity consideration in this spotlight. We are also grateful to Mary Naylor, PhD, RN, FAAN, director of the New Courtland Center for Transitions and Health, for her thoughtful contributions to this research and her review of this spotlight.

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- 1 Albert Siu and Linda V. DeCherrie, "Inside Mount Sinai's Hospital-at-Home Program." *Harvard Business Review*, May 10, 2019, <https://hbr.org/2019/05/inside-mount-sinai-hospital-at-home-program>.
  - 2 Susan C. Reinhard et al., *Home Alone Revisited: Family Caregivers Providing Complex Care* (Washington, DC: AARP Public Policy Institute, April 2019), <https://www.aarp.org/content/dam/aarp/ppi/2019/04/home-alone-revisited-family-caregivers-providing-complex-care.pdf>.
  - 3 "History," *Hospital at Home*, 2012, <https://www.hospitalathome.org/about-us/history.php>.
  - 4 Linda V. DeCherrie et al., "Hospital at Home: Setting a Regulatory Course to Ensure Safe, High-Quality Care," *Joint Commission Journal on Quality and Patient Safety* 48, no. 3 (2022): 180–84, <https://doi.org/10.1016/j.jcjq.2021.12.003>.
  - 5 *Ibid.*
  - 6 "CMS Announces Comprehensive Strategy to Enhance Hospital Capacity Amid COVID-19 Surge," *CMS Newsroom*, Centers for Medicare & Medicaid Services, November 25, 2020, <https://www.cms.gov/newsroom/press-releases/cms-announces-comprehensive-strategy-enhance-hospital-capacity-amid-covid-19-surge>.
  - 7 "Acute Hospital Care at Home," *QualityNet*, Centers for Medicare & Medicaid Services, <https://qualitynet.cms.gov/acute-hospital-care-at-home/resources>.
  - 8 *Ibid.*
  - 9 AARP PPI and ATI Advisory, conducted research and interviews, 2021–22.
  - 10 *Ibid.*
  - 11 G. A. Caplan et al., "Hospital in the Home: A Randomised Controlled Trial," *The Medical journal of Australia* 170, no. 4 (1999): 156–60, <https://pubmed.ncbi.nlm.nih.gov/10078179>.
  - 12 Bruce Leff et al., "Comparison of Stress Experienced by Family Members of Patients Treated in Hospital at Home with That of Those Receiving Traditional Acute Hospital Care," *Journal of the American Geriatrics Society* 56, no. 1 (2007), <https://doi.org/10.1111/j.1532-5415.2007.01459.x>.
  - 13 Jacques Lemelin et al., "Patient, Informal Caregiver and Care Provider Acceptance of a Hospital in the Home Program in Ontario, Canada," *BMC Health Services Research* 7, no. 1 (2007), <https://doi.org/10.1186/1472-6963-7-130>.

- 14 Alicia L. Best et al., “Institutional Distrust among African Americans and Building Trustworthiness in the COVID-19 Response: Implications for Ethical Public Health Practice,” *Journal of Health Care for the Poor and Underserved* 32, no. 1 (2021): 90–98, <https://doi.org/10.1353/hpu.2021.0010>.
- 15 Laura Skufca and Chuck Rainville, *Caregiving Out-of-Pocket Costs Study 2021* (Washington, DC: AARP Research, June 2021), <https://doi.org/10.26419/res.00473.001>.
- 16 Reinhard et al., *Home Alone Revisited*.
- 17 AARP PPI and ATI Advisory, conducted research and interviews, 2021–22.
- 18 Ibid.
- 19 Ibid.
- 20 Hospital Inpatient Services Modernization Act, 117th Cong., 2nd session (March 10, 2022), [https://www.carper.senate.gov/public/\\_cache/files/2/2/22d48399-8927-4c43-aea4-27acf84d0677/4DD27D252D6AAA48F9D5CA23C4A765AF.kel22125.pdf](https://www.carper.senate.gov/public/_cache/files/2/2/22d48399-8927-4c43-aea4-27acf84d0677/4DD27D252D6AAA48F9D5CA23C4A765AF.kel22125.pdf).

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Spotlight 1445201, August 2022

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