

# Developing Competencies for Pediatric Hospice and Palliative Medicine

## abstract

FREE

In 2006, hospice and palliative medicine (HPM) became an officially recognized subspecialty. This designation helped initiate the Accreditation Council of Graduate Medical Education Outcomes Project in HPM. As part of this process, a group of expert clinician–educators in HPM defined the initial competency-based outcomes for HPM fellows (General HPM Competencies). Concurrently, these experts recognized and acknowledged that additional expertise in pediatric HPM would ensure that the competencies for pediatric HPM were optimally represented. To fill this gap, a group of pediatric HPM experts used a product development method to define specific Pediatric HPM Competencies. This article describes the development process. With the ongoing evolution of HPM, these competencies will evolve. As part of the Next Accreditation System, the Accreditation Council of Graduate Medical Education uses milestones as a framework to better define competency-based, measurable outcomes for trainees. Currently, there are no milestones specific to HPM, although the field is designing curricular milestones with multispecialty involvement, including pediatrics. These competencies are the conceptual framework for the pediatric content in the HPM milestones. They are specific to the pediatric HPM subspecialist and should be integrated into the training of pediatric HPM subspecialists. They will serve a foundational role in HPM and should inform a wide range of emerging innovations, including the next evolution of HPM Competencies, development of HPM curricular milestones, and training of adult HPM and other pediatric subspecialists. They may also inform pediatric HPM outcome measures, as well as standards of practice and performance for pediatric HPM interdisciplinary teams. *Pediatrics* 2014;134:e1670–e1677

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### KEY WORDS

competencies, hospice and palliative medicine, milestones, pediatric palliative care, fellowship training

### ABBREVIATIONS

AAHPM—American Academy of Hospice and Palliative Medicine  
AAP—American Academy of Pediatrics  
ACGME—Accreditation Council of Graduate Medical Education  
HPM—hospice and palliative medicine

Dr Klick conceptualized and designed the project, recruited participants, facilitated the iterative development process, secured American Academy of Hospice and Palliative Medicine and American Academy of Pediatrics support, carried out the initial data analysis, and drafted the initial manuscript; Dr Friebert conceptualized and designed the project, recruited participants, participated in the iterative development process, secured American Academy of Hospice and Palliative Medicine and American Academy of Pediatrics support, performed data analysis, and critically reviewed and revised the manuscript; Drs Hutton, Osenga, Pituch, Vesel, and Weidner participated in the iterative development process, performed data analysis, and reviewed and revised the manuscript; Drs Block and Morrison helped conceptualize and design the project and critically reviewed and revised the manuscript; and all authors approved the final manuscript as submitted.

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Hospice and palliative medicine (HPM) became an official medical subspecialty in 2006 when the American Board of Medical Specialties and the Accreditation Council of Graduate Medical Education (ACGME) formally recognized HPM as a discipline. With support from 10 cosponsoring boards (anesthesiology, emergency medicine, family medicine, internal medicine, obstetrics and gynecology, pediatrics, physical medicine and rehabilitation, psychiatry and neurology, radiology, and surgery), HPM was established as 1 subspecialty encompassing the care of patients of all ages with serious and life-threatening conditions.

HPM board certification and fellowship accreditation standards transitioned into the American Board of Medical Specialties and ACGME Outcome Project framework.<sup>1–3</sup> This framework emphasizes competence in key domains and the measurable outcomes of educational experiences, organized around 6 central competencies: Patient and Family Care, Medical Knowledge, Practice-Based Learning and Improvement, Interpersonal and Communication Skills, Professionalism, and Systems-Based Practice.

At the same time, 12 leaders in the field of HPM developed the initial competency-based outcomes for HPM (HPM Competencies), which now guide all fellowship training in HPM. The HPM Competencies are a tool “to inform and strengthen HPM fellowship training by defining the outcome of HPM fellowship training—the development of a ‘competent hospice and palliative medicine subspecialist physician’ who has progressed through novice and advanced beginner levels, and is moving towards the proficient and expert levels of competency, as described by the Dreyfus hierarchy.”<sup>4–6</sup>

### STATEMENT OF NEED

Because the majority of patients with life-threatening conditions are adults, and most HPM fellowship training programs are focused on the needs of adult

patients and their families, the HPM competencies focus on care for adult patients. Although they provide excellent guidance for any HPM provider, as the authors explicitly acknowledge, they do not address the unique skillset needed to provide palliative care to pediatric patients.<sup>4</sup>

The field of pediatric HPM is rapidly growing. Almost 50% of all pediatric hospitals have a pediatric HPM program, with most established within the past 10 years.<sup>7</sup> In 2008, only 3 institutions and 3 positions were available for specialized training in pediatric HPM. As of June 2014, 15 institutions with 20 positions are available for pediatric focused training. Specific competencies for the pediatric HPM subspecialist are needed. In answer to that need, a group of 8 clinician–educators in pediatric HPM, the Pediatric HPM Competencies Work Group, initiated a process to establish competency-based outcomes specific to pediatric HPM (Pediatric HPM Competencies).

### METHODS

In 2008, the Pediatric HPM Competencies Work Group undertook the development of Pediatric HPM Competencies. Importantly, the group determined that the HPM Competencies would be an appropriate template for the development of the Pediatric HPM Competencies.

One of the most challenging aspects of competency design is that many tasks must be performed simultaneously. The 6 core competencies cannot exist in isolation (they are interrelated, and a physician must possess skills, knowledge, and attitudes in all 6), and each must be treated as an interdependent part of the other 5. Changes in patient care must inform and effect change in all competencies simultaneously. Content and edits must be incorporated continuously until the final product is realized. Design requires flow of information across simultaneous tasks and feedback to inform iteration of earlier tasks. The

workgroup approached this challenge through an accepted engineering product design method.<sup>8</sup>

In this process, the competencies as a whole are considered the product, and the 6 individual core competencies are separate design pieces of the larger product. Completion of the design includes many iterations of information sharing to ensure that each competency is appropriately weighted and influenced by decisions made by reviewers.

The following essential elements were determined before initiation of the project.

A = Formation of the workgroup, agreeing on mission and design process, standardizing workflow

B = Systematic review of the current literature and content (eg, current competencies)

C = Workgroup review and edit of Patient Care to Pediatric Competency

D = Workgroup review and edit of Medical Knowledge to Pediatric Competency

E = Workgroup review and edit of Practice-Based Learning and Improvement to Pediatric Competency

F = Workgroup review and edit of Interpersonal and Communication Skills to Pediatric Competency

G = Workgroup review and edit of Professionalism to Pediatric Competency

H = Workgroup review and edit of System-Based Practice to Pediatric Competency

I = Review from experts in the field of Pediatric Palliative Care

J = Survey review from members of the field

K = Final product

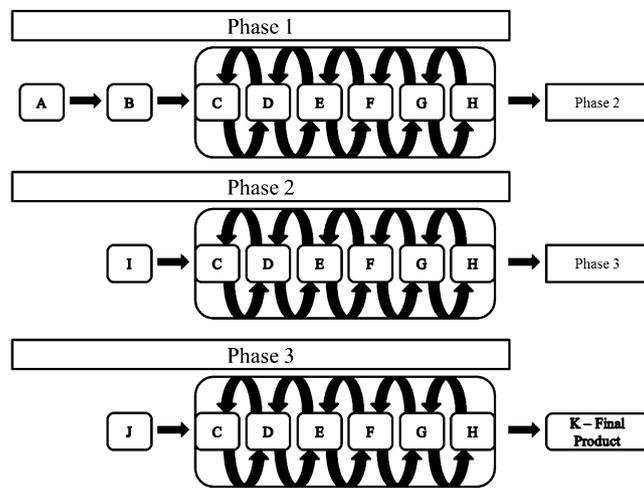
In this project task list, some tasks are independent (A and B), some are interdependent (C–H), and some must occur later but also to previous tasks (I and J).

In the design process, formation of the workgroup (A) must occur before systematic review of the current competencies (B). Review and editing of each core competency (steps C–H) are separate tasks that must occur simultaneously. After initial review and revision, experts in the field must review the content and inform a second review and revision of each core competency. This iterative review-and-revise process is then followed until review yields no additional revision.

To manage this complex process over time, the workgroup divided these tasks and iterations into 4 phases (Fig 1).

Phase 1 (tasks A–H) focused on evaluating the HPM Competencies and designing the content essential to the Pediatric HPM Competencies working document. The workgroup initiated this phase with an in-person meeting to set the goals, objectives, and methods for developing the pediatric HPM competencies. Subsequently, the group worked iteratively to review and revise the HPM Competencies document (version 2.3) into a working document of Pediatric HPM Competencies. Each member was then responsible for evaluating 1 of the 6 core competencies (with medical knowledge and patient care each assigned 2 members), suggesting revision to better represent pediatric care, and facilitating conference calls to vet suggested changes. Next, the group had 2 additional in-person meetings to review the changes as a complete document and to establish steps for dissemination and obtaining feedback.

Phase 2 (task I with iteration of tasks C–H) focused on dissemination, review, and refinement of the working document from the pediatric HPM field. The review and comment period started with a formal presentation at the 2011 American Academy of Hospice and Palliative Medicine (AAHPM) and Hospice and Palliative Nursing Association Annual Assembly, where feedback was solicited from attendee focus groups on utility, impact,



**FIGURE 1** Sequence of design of the Pediatric HPM Competencies.

ease of use, and next steps. This presentation included an early draft of the Pediatric HPM Competencies document and highlighted the work done in Phase 1. Next, the workgroup solicited specific feedback from clinician-educators in both pediatric and adult HPM. These people were identified for their leadership roles in program development, education, fellowship training, or research and their experience in clinical palliative care. The workgroup again solicited specific feedback about the utility, impact, ease of use, and additional steps for the pediatric competencies.

In Phase 3 (task J with iteration of C–H), a formal e-mail–based survey was disseminated to members of the American Academy of Pediatrics (AAP) Section on Hospice and Palliative Medicine and members of the AAHPM Pediatric, Fellowship Directors, and Program Chiefs Special Interest Groups. The survey was developed through an iterative process by the workgroup and input from staff of the AAP and AAHPM. Data were collected on the respondents' primary clinical role as physicians or other interdisciplinary team members, experience in education and fellowship training, primary focus in pediatrics or other populations, and level of clinical experience in HPM. Respondents then rated their level of support

for how each of the 6 core competencies was represented in the document, their opinion of the level of detail included, any identified competencies that were not addressed, and general opinion about whether the competencies adequately covered the knowledge, skills, and attitudes needed to care for pediatric patients. Specific comments were also solicited for each question.

Responses from the initial focus group, the experts in the field, and the formal survey were recorded and distributed to the workgroup. Two members of the workgroup identified common themes represented in all of the feedback, responses, and comments, which were then vetted via conference call. Initially the workgroup discussed the possibility of weighting the levels of feedback, giving the clinical education experts' input more impact. In the process of analyzing the feedback and comments, however, it was discovered that the themes were consistent throughout the 3 levels, and therefore no weighting was necessary. These themes are discussed later.

The feedback, responses, and comments were compiled and evaluated by the workgroup. Again, each member was responsible for 1 competency, evaluating proposed changes within the themes and proposing specific edits

to the competencies document. These changes were then vetted via conference call and incorporated into the working document.

Two members of the workgroup reviewed each comment in detail and devised 6 thematic codes<sup>9</sup> that encompassed all comments from the 101 responses. These themes were similar to the discussions of the workgroup and the feedback from the expert review, and they provided the core of the iterative editing of the competencies and are discussed later.

In editing the competencies, the workgroup placed priority on Phase 1 (workgroup review) followed by Phase 2 (expert review) and Phase 3 (survey responses). The amount of feedback diminished and the amount of agreement increased significantly as the workgroup progressed through the steps of the design process. This convergence of feedback and agreement suggests that the final competencies provide an effective consensus of the core competencies for pediatric HPM.

Phase 4 focused on ensuring effective collaboration with the initial HPM Competencies Work Group and on securing the support of the AAHPM and the AAP. In their current state, these competencies are supported by both the AAP and the AAHPM.

## RESULTS

Three significant results are detailed in this article:

Content of the Pediatric HPM Competencies

Themes discovered in the review and refinement of the Pediatric HPM Competencies

Data obtained from the formal survey evaluating the Pediatric HPM Competencies

### The Pediatric HPM Competencies

The intent of this project was to produce a competency document that

represents the knowledge, skills, and attitudes essential for the practice of pediatric HPM, organized into the 6 core competencies described by the ACGME: Patient and Family Care, Medical Knowledge, Practice-Based Learning and Improvement, Interpersonal and Communication Skills, Professionalism, and Systems-Based Practice. The document includes the specific competencies and supplemental contextual information,<sup>10–16</sup> and it can be freely accessed on the Web pages of both the AAP and the AAHPM.

### Qualitative Evaluation of Data: Themes From Design, Dissemination, Review, and Refinement

The themes that emerged during the iterative process of designing the competencies were consistent across the workgroup, expert review, and formal survey. These themes represented the chief points of discussion and dissent throughout the design process.

### Overall Impressions of the Document

As a whole, reviewers thought the competencies captured the major themes of providing pediatric hospice and palliative care. In addition, they appreciated the connection to the General HPM Competencies and could see real utility in evolving these into learning objectives for their own education programs.

The most common criticisms suggested that the competencies “need(ed) better organization”; were “too long” and “too specific,” with too many “parameters” and “details”; or were simply “overwhelming.” In general, the comments drew attention to the fact that these competencies are difficult to translate into a useful tool that will improve outcomes in physician education and patient care.

### Concision Versus Specificity

The General HPM Competencies struggled to balance concision and specificity in

wording,<sup>4</sup> aiming to provide both breadth, to define the unique aspects of HPM, and depth, to offer specific guidance on expected measurable outcomes. Simultaneously, priority was placed on concision to avoid excessive monitoring and measurement requirements. The workgroup attempted to maintain a similar balance in the Pediatric HPM Competencies. As the field moves forward in the ACGME Milestones framework,<sup>17</sup> the competencies will serve as a strong base from which to find an optimal balance.

### Requiring Different Competencies in Different Settings

The General HPM Competencies also struggled to define the different expectations for a specific competency in different clinical settings.<sup>4</sup> The patient's location in his or her disease trajectory (“upstream,” at the end of life, or somewhere in between) has a major effect on location of care and the knowledge, skills, and attitudes essential to care for that patient.

For example, a subspecialist caring for patients enrolled in a community hospice will need in-depth knowledge of how to manage challenging end-of-life symptoms in a low-tech, low-resource environment; expertise in educating family members about caring for a loved one at home; and competence in understanding the complexities of the Medicare or Medicaid hospice benefit and how they apply to pediatric patients. In contrast, a subspecialist caring for children in a pediatric hospital where patients are receiving disease-modifying therapies will need detailed knowledge about complex disease management, disease-specific therapies, and high-tech treatments, as well as skills for moderating recommendations from multiple subspecialists.

Regardless of setting, however, pediatric HPM subspecialists must be able to manage and clarify goals of care

for patients and families that often simultaneously pursue disease-modifying and palliative therapies. Furthermore, the pediatric HPM subspecialist may be called on to care for patients in multiple settings and will need a degree of competence in each. Although this issue is not pediatric-specific, the subtleties, resources, and settings are unique to pediatric HPM and require specific demonstration and evaluation.

### Connecting Competencies to Assessment, Measurement, and Outcomes

The detail in the Pediatric HPM Competencies created concern about the burden of assessment and implementation. Tools and strategies to assess these new competencies are needed and lacking, and developing, piloting, and validating such tools takes great effort and resources. Fortunately, the HPM Outcomes Project (Phase 3 and 4) has developed and packaged an assessment toolkit for this purpose.<sup>18</sup> Though not validated and not all-inclusive, this toolkit provides a starting point for approaching these challenges and for connecting competencies to outcome measures and the milestone framework.

Furthermore, although detailed pediatric HPM competencies will be of value to the learner as they define the knowledge, skills, and attitudes that must be mastered, the value to the program director may be more complex. The field is diverse, with a wide range of diagnoses, trajectories, clinical settings, and levels of expertise. Designing curricula that make growth in these competencies achievable may be difficult. To date, training programs in this field have consistently found creative ways to provide mentorship, teamwork, didactic and clinical experiences with patients and families, and meaningful feedback through which trainees can build competence.

Growth of the field will place even more emphasis on such innovation and collaboration.

### Quantitative Evaluation of Data From the Formal Survey

The formal survey-based review of the Pediatric HPM Competencies demonstrated strong support from the field. In all, 101 responses were received (response rate not applicable due to open distribution). Of these, 62% of respondents cared primarily for pediatric patients, and 44% focused on adult or geriatric patients (some respondents practiced both adult medicine and pediatrics). Furthermore, 94% were physicians and 5% nurse practitioners or physician assistants. Most had experience in graduate medical education, but only 46.9% taught HPM fellows, with 19.4% having taught pediatric HPM fellows. Only 23.8% of respondents spent more than 50% of their clinical time focused on pediatric HPM, with another 15.8% spending between 25% and 50%. Furthermore, 45.5% of respondents had not served as formal faculty in a training program, although 29.7% spent >6 months of the year involved in training or educating professionals in pediatric HPM.

Although the major themes identified were critical of certain aspects of the document, support for the individual competencies was strong (Tables 1, 2, and 3).

Finally, respondents were asked how they anticipate using these competencies (Table 4).

## DISCUSSION

### Unique Aspects of Pediatric HPM Training and Practice

The 10 cosponsoring boards for HPM fellowship and board certification intended the field of HPM to be 1 subspecialty, caring for patients across the age spectrum. However, this approach has introduced certain challenges in defining, administering, and managing the field because of specific differences in the care of pediatric, adult, and geriatric patients.

In general, the approach has worked well, in part because of the flexibility of the managing boards and the fact that there are more similarities than differences in the palliative care core competencies across the age spectrum. However, the differences suggest that some attention must be paid to the subfields of HPM specifically focused on the care of pediatric, adult, or geriatric patients. These subfields have unique challenges in training, workforce, and clinical care that must be identified, acknowledged, and addressed.

### Clinical Care: Differentiating Pediatric and General Competencies

In developing these competencies, the workgroup aimed to differentiate a pediatric and general HPM subspecialist and to define the core knowledge, skills, and attitudes unique to the care of pediatric patients. As they did so, it became clear that many of the basic

**TABLE 1** To What Degree Do You Support the Competencies Described?

Core Competency	Support, %	Do Not Support, %	Support With Modifications, %
Patient and Family Care	90.4	0.0	9.6
Medical Knowledge	93.2	0.0	6.8
Practice-Based Learning and Improvement	95.8	0.0	4.2
Interpersonal and Communication Skills	95.8	0.0	4.2
Professionalism	97.3	0.0	2.7
Systems-Based Practice	95.7	1.4 <sup>a</sup>	2.9

<sup>a</sup> The single negative respondent stated, "I cannot figure out what 'systems-based practice' means or should mean. It's nonsensical jargon."

**TABLE 2** Within each of the 6 domains, do the competencies contain an appropriate level of detail?

Core Competency	Too Much Detail, %	Right Amount of Detail, %	Not Enough Detail, %
Patient and Family Care	20.0	78.6	1.4
Medical Knowledge	15.7	81.4	2.9
Practice-Based Learning and Improvement	10.0	84.3	5.7
Interpersonal and Communication Skills	11.4	84.3	4.3
Professionalism	15.7	80.0	4.3
Systems-Based Practice	11.4	84.3	4.3

**TABLE 3** Do the Proposed Competencies Adequately Cover the Core Knowledge, Skills, and Attitudes Needed in the Care of Pediatric Patients?

Yes	83.1%
I'm not sure	15.5%
No	1.4%

core competencies, as written by the HPM Competency Work Group, are universal across the age spectrum and fit well for pediatric patients (eg, although the choice of appropriate analgesic and specific dosing may be different in the care of a neonate, the approach to and challenges of symptom management are very similar).

However, significant differences do exist in HPM when one is caring for a child: bereavement is different after the loss of a child; a child's physiology is different and must be seen in the context of constant change and growth; communication with children, including their integration in clinical decisions, must be considered in the context of their cognitive ability, developmental stage, and family structure; and care teams may suffer differently when caring

for a child with a life-threatening condition, for example.

Currently, many of the unique aspects of the care of pediatric patients with serious illness are poorly described in the medical literature. The field of pediatric HPM needs to more clearly define and broaden its understanding of these differences. Consequently, compared with the General HPM Competencies, a number of core areas of knowledge, skill, and attitude in the Pediatric HPM Competencies were added *de novo* (eg, specifics in communication with children), were emphasized (eg, development and decision-making for children), or were eliminated (eg, examples of conditions and symptoms unique to nonpediatric populations). Over time, as other areas in need of additions, changes, or more emphasis are identified, these competencies will also need to evolve.

### Workforce Challenges and Training Opportunities in Pediatric HPM

HPM subspecialists are scarce. In pediatrics the shortage is particularly severe and is coupled with a lack of

pediatric-focused community resources.<sup>19</sup> This workforce challenge requires that adult HPM subspecialists care for pediatric patients in some settings. Even with growth in the field of pediatric HPM, it is unlikely that there will ever be enough pediatric HPM subspecialists to meet the growing demand for services. This imbalance means that both pediatric and adult HPM subspecialists must develop specific competence in collaborating with each other in the care of pediatric patients.

Pediatric HPM training opportunities for both pediatric and adult HPM subspecialists are similarly scarce. Although there is a clear need to improve the availability of training opportunities, the field must decide where to focus its efforts: on facilitating immediate training of adult HPM subspecialists to meet the current need or on training pediatric HPM subspecialists to develop pediatric HPM as a clinical and academic subspecialty.

On this challenge, the workgroup was divided. Developing pediatric training opportunities for adult HPM subspecialists takes less time and fewer resources, mostly because these rotations are often short and do not require the same level of evaluation and assessment. However, such training does not increase the availability of pediatric HPM subspecialists, develop new clinical or training programs, or advance the knowledge base through research. In contrast, developing pediatric HPM training programs requires significantly more time and resources but offers the best chance for the long-term growth of the pediatric HPM field.

The solution may be found in a third mandate: developing pediatric tracks within adult HPM training programs. The pediatric HPM subspecialist would receive pediatric HPM training while having access to the resources and training opportunities of the adult HPM training program; similarly, the adult HPM subspecialist would have access to

**TABLE 4** How do you anticipate using the pediatric HPM competencies (may choose more than one)?

	%
To ensure that my fellowship program adequately addresses pediatric competencies	36.8
To develop a new pediatric-focused fellowship training program	22.1
To develop new evaluation strategies	36.8
To develop new education opportunities for medical students	44.1
To develop new training opportunities for residents	60.3
To develop new training opportunities for non-HPM fellows	23.5
To inform the education and training of non-HPM fellows (eg, critical care, oncology)	44.1
Other (please specify): To inform administration and legislative parties about pediatric HPM; to develop curricular milestones; for ongoing competence training and continuing medical education; for graduate medical education curricular planning	14.7

pediatric HPM training opportunities. In the end, both subspecialties would benefit from better collaboration in program development and from conservation of resources.

Toward this end of merged training, it is conceivable that, over time, a single set of general HPM competencies may emerge that fully describe the competencies that all HPM providers must master. Fellowship programs would provide training in the general competencies to all learners. Focused competencies, such as the Pediatric HPM Competencies, could then be used to enhance training of physicians intending to focus on pediatric patients.

### Growth of Pediatric HPM

The field of pediatric HPM will undoubtedly change significantly in the years to come. Programs will need to evolve to provide more educational opportunities and incorporate more robust scholarly activities. These areas of growth will improve the knowledge base of pediatric HPM and inform the care of pediatric patients with serious and life-threatening conditions and their families. To accomplish this, members of the pediatric HPM community will have to take leadership roles in creating training programs and educational opportunities for all trainee levels.

### Competencies, Outcome Measures, Milestones, and the Next Accreditation System

In design and in practice, the competencies described herein represent a long list of the skills, knowledge, and attitudes that are essential to being a pediatric palliative care physician. However, they do not define measurable outcomes for learning experi-

ences, nor do they describe the typical development of a learner in the field. Developing outcome measures for the learner in each of these competencies will be challenging.

As the field of HPM moves forward, these competencies will have to evolve into an outcome-based evaluation of physicians. In the Next Accreditation System, the ACGME uses milestones as a framework for measurable outcomes.<sup>17,20</sup> For example, in 2013 the ACGME released a list of milestones for a small group of medical specialties (eg, internal medicine, pediatrics).<sup>21</sup> Currently, there are no milestones specific to HPM, although the field is now working toward them with multi-specialty involvement, including pediatrics. These competencies will be an important stepping stone in the development of specialty-specific milestones. The detail and specificity of the competencies document will provide an essential foundation for thinking through the typical development of a learner in the field.

### CONCLUSIONS

For now, the Pediatric HPM Competencies are specific to pediatric HPM subspecialists and should be integrated into their training. In the future, they will serve a foundational role in the field of HPM, inform a wide range of emerging innovations, and provide a framework for dealing with challenges.

In HPM, they should be incorporated into the next evolution of HPM Competencies. Specifically, they should be used in designing the HPM Milestones that will better define and improve the effectiveness of outcome measures for learners.

In pediatrics, they should be refined for use in training other pediatric subspecialists (eg, critical care, oncology) and learners at other stages of development (eg, medical students, residents).

In pediatric HPM, they should inform the development of standard-of-practice and performance-improvement initiatives for HPM subspecialists and interdisciplinary teams, as well as outcome measures for palliative care patients.

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