NEW YORK STATE | Department of Health

Delivery System Reform Incentive Payment Program

Projects 3.g.i and 3.g.ii: Palliative Care Measures

Contents

Introduction

The New York Delivery System Reform Incentive Payment (DSRIP) Program projects 3.g.i and 3.g.ii aim to further integrate palliative care into patient-centered medical home (PCMH) practices and nursing home settings. The goal of these projects is to measure access to palliative care services for patients most in need. DOH does not intend to evaluate the outcomes associated with palliative care interventions, but rather that the interventions are made available through the normal course of care. Both projects use the Integrated Palliative Care Outcome Scale (IPOS), a standardized screening tool to identify which patients are most in need of palliative care interventions.

Background

Initially, data collected from New York State's Uniform Assessment System (UAS-NY) served as the foundation for the project measures and performance evaluation. The UAS-NY tool was developed to facilitate assessments for long-term care and community-based programs in New York State. As the PPS implementation plans were reviewed, it became apparent that there would be little overlap between the population in the long-term care and community-based programs and the targeted palliative care populations in the PPS project plans. Use of the UAS-NY results would not allow robust evaluation of the improvement of palliative care access in the projects because of the mismatch in target populations. Additionally, the UAS-NY requires a significant time commitment (up to four hours per patient) in order to collect patient information which is used in quality measures. Finally, the UAS-NY derived measures related to only two palliative care outcomes (pain management and advanced directives).

Given the limited overlap in targeted populations, significant data collection burden and the misalignment between measures available in the UAS-NY tool and the goal of the palliative care projects, DOH decided to find an alternate assessment tool, to more clearly assess access to palliative care through these projects. This document outlines the use of this new proposed tool and accompanying measures.

DOH conducted a literature review yielding 73 separate palliative care assessment tools used across a variety of patient types and settings. DOH considered the effectiveness of these tools across several dimensions, including the ability to accurately measure physical symptoms and the emotional, psychological, and spiritual needs of individuals receiving palliative care. DOH also considered the administrative burden required to implement these assessment tools.

DOH ultimately determined that the Integrated Palliative Care Outcome Scale (IPOS)[1] was the most suitable assessment tool for the two projects. The IPOS is widely used and can be self-administered or completed by health care staff in fewer than 10 minutes. While the tool has been used to improve palliative care outcomes at a patient-specific level, for the purposes of DSRIP, DOH intends to use this tool to evaluate a provider's ability to increase the infrastructure necessary for expanding palliative care services to patients most in need.

Two systematic reviews, published in 2011 and 2015, found a total of 78 articles (35 and 43 respectively) reviewing the use or validation of the POS, an earlier version of the IPOS.[2,3] Many of these reviews also included evaluations of a similar palliative care screening tool: The Support

[1] http://pos-pal.org/maix/background.php
[2] Collins, Emily S., et al. "A Systematic Review of the Use of the Palliative Care Outcome Scale and the Support Team Assessment Schedule in Palliative Care." Journal of pain and symptom management (2015).
[3] Bausewein, C., et al. "The use of two common palliative outcome measures in clinical care and research: A systematic review of POS and STAS." Palliative medicine (2011).

Team Assessment Schedule (STAS) tool. The STAS is used by staff members to assess a patient's care across similar measures as the POS (including the acuity levels of patient symptoms and anxiety), and has been validated in similar care settings. However, support for the POS has steadily increased over the past several years, while comparatively, advocacy for the use of STAS has remained stagnant.[4] The most commonly cited reasons for use of the POS over the STAS include:

- The POS is shorter than the STAS at 11 questions versus 17
- The POS has patient, staff, and family versions of the survey, compared to only the staff version of the STAS
- The free text option in the POS allows for more open responses from the assessment respondent
- The patient-completed POS has the lowest risk of biased responses[5]

The IPOS is the newest development by the Cicely Saunders Institute to assess palliative care, focusing on similar dimensions and concerns as the POS but with a greater focus on patient symptoms and mood. The IPOS has 10 questions with slightly updated phrasing to the previously considered POS version.

The transition from UAS-NY to IPOS for the purposes of DSRIP allowed for more flexibility in measure selection. Prevailing academic literature surrounding the objectives of palliative care indicate five leading areas of patient status management as critical when designing successful palliative care programs. These five areas are focused on measuring patient pain and symptom management, perceptions of life worth, levels of self-esteem, and the presence of advance directives for the purposes of delivering palliative care interventions.[6] Four of these areas are directly captured through questions contained in the IPOS tool; the fifth is addressed through a question used in the New York State Medical Orders for Life-Sustaining Treatment (MOLST) form.

Both 3.g.i and 3.g.ii aim to increase access to palliative care interventions for patients with the greatest need based on responses to the five questions outlined above. Practices and nursing homes are expected to engage patients through open conversations, additional psychological and social assessments, specialty resource referrals, and patient and family education. Documentation of the intervention offered or delivered will measure the practice or nursing home's ability to respond to the individual needs of the patient and further enhance the patient's access to palliative care services. Examples of these types of interventions may include counseling, further assessment, exploring care treatment options, support referrals, or medication management. By providing or offering appropriate interventions for patients who demonstrate need, PPS can work toward the project's goal of improving access to palliative care when necessary.

[4] Between 2011 and 2015, more than four times the number of publications related to positive reviews of the POS were published compared to STAS.
[5] Bausewein, C., et al. "The use of two common palliative outcome measures."
[6] Institute of Medicine (2014). Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life.

Administrative Guidance

Implementation

Target Population

The possible target populations for projects 3.g.i and 3.g.ii include patients receiving palliative care services who are also either enrolled in a PCMH or currently residing in a nursing home. Participation in palliative care is voluntary and patients/families may choose not to complete assessments or to discontinue participation in palliative care at any time. Palliative medicine providers optimize disease management through comprehensive assessment, symptom management, and supportive care to patients and caregivers.[7] This model of care enhances quality of life from the curative/restorative care stage through caregiver bereavement. DOH however is not defining palliative care services strictly by identifying acceptable payment codes and / or any other specific service. Rather, PPS are responsible for identifying patients who are receiving palliative care services through the definition they used when estimating active engagement populations for projects 3.g.i and 3.g.ii.during the initial DSRIP application process. Practices and nursing homes should inform targeted patients of the benefits of palliative care and if patients elect to complete the survey, efforts should be made to inform them of the use of the data obtained. As the survey asks only if an intervention was offered (and not necessarily performed), performance will not be adversely affected by non-compliant patients. If the patient is impaired, the assessment specifically designed for non-responsive or incapable patients can be used.

The actively engaged definition for patient engagement remains consistent with original guidance offered during the PPS application process. The target populations for this measure, those who should receive the IPOS survey, are individuals falling under the actively engaged definitions included below. For projects 3.g.i and 3.g.ii, the actively engaged definition, counting criteria and data source are as follows:

Project 3.g.i: Integration of Palliative Care into the PCMH Model

Actively Engaged Definition	The number of participating patients receiving palliative care services at participating PCMH sites, in accordance with the adopted clinical guidelines.
Counting Criteria	A count of patients who meet the criteria over a 1-year measurement period. Duplicate counts of patients are not allowed. The count is not additive across DSRIP years.
Data Source	EHRs or other IT Platforms (i.e. patient registries).

Project 3.g.ii: Integration of Palliative Care into Nursing Homes

Actively Engaged Definition	The number of participating patients receiving palliative care services at participating nursing home sites, in accordance with the adopted clinical guidelines.

[7] Institute of Medicine, Dying in America. Pg. 5-4

Counting Criteria	A count of patients who meet the criteria over a 1-year measurement period. Duplicate counts of patients are not allowed. The count is not additive across DSRIP years.
Data Source	EHRs or other IT Platforms (i.e. patient registries).

Assessment Versions

Three versions of the IPOS are available: a patient version (self-administered or administered by a family member/caregiver), a staff version, and a version for patients who are not responsive or incapable of completing their own survey or relaying information regarding their own health and well-being (this version can be completed by staff, family members, or any other primary giver without significant prior training). All three of these assessments are provided in Appendix A. It is important to note that the versions included in this guidance document also contain the additional question related to the use of advanced directives as well as additional fields which will not be present on other publicly available versions of the IPOS.

Assessment Administration

Assessments should be administered to eligible populations when the patient:

- Enters a palliative care treatment regime (or as soon as possible if already participating)
- Experiences a significant change in patient status (defined as changes to the patient's care plan, such as hospitalization, changes in home care needs, independent living status)
- Is being routinely monitored six months from the previous assessment.

In addition to these specific conditions - assessments should also be conducted on all eligible patients at least once every six months.

Patient-reported outcome measures such as the IPOS are increasingly recognized as vital in informing the delivery of healthcare, yet there are many challenges in implementing these types of survey instruments specific to their use among patients receiving palliative care services. When choosing a method for administering the IPOS, PPS should consider the setting, the patients physical and mental well-being as well as available staff resources. The IPOS contains several questions assessing a patient's physical, mental and spiritual well-being and could adversely affect certain patients in certain situations. As such, the survey is designed to be implemented in several ways (including in-person, over the phone or through an e-consultation) throughout the course of a patient's care which should be considered when planning implementation strategies:

- The IPOS can be left behind with patients able to self-complete the survey. Practices that are leaving the IPOS with patients may consider creating a relaxed atmosphere, attaching a brief cover note explaining the use of the IPOS, including a verbal explanation of the use of the IPOS before allowing the patient to complete the survey, and reassuring the patient that there are no right or wrong answers.
- The IPOS can be administered by staff, whether to guide patients in self-administration, or to verbally administer the questions. In this approach, staff can ensure that patients feel relaxed, can answer questions which may arise during the administration of the survey, and can take note of any non-verbal cues.
- The IPOS can be integrated into the course of a conversation as part of a larger, holistic assessment of the patient. In this manner, the IPOS can be used as a conversational guide, allowing providers to understand patients' goals of care, to follow-up on symptom management, and to include the questions as part of a larger clinical assessment[8].

[8] Guidance on the implementation of Patient Reported Outcome Measures (PROMs) in clinical palliative care: With a focus on the POS Family of measures. http://pos-pal.org/doc15/PROMS_booklet_FINAL_15102015_compressed.pdf.

Interventions may be offered or provided, and could vary widely**.** Interventions may include but are not limited to:

- Counseling and management recommendations
- Patient education
- Further assessments
- Medication management
- Exploring further care treatment options
- Support referrals and interventions for family and caregivers (support, education, referral assistance)

If an intervention has been offered corresponding to a patient response indicating a need, staff must indicate this in the appropriate space provided on the assessment form. One intervention can address the needs of patients indicated across more than one question. That intervention however should specifically address the sources of each question indicating a need for an intervention. The assessment form includes only binary questions documenting whether interventions were offered or provided. While no details on the intervention will be documented on the assessment form, the practice or nursing home will be required to maintain evidence for these interventions within patient medical records which may be subject to an audit following submission.

Training

DOH recommends training all staff members involved in the assessment administration to ensure consistency in both results and interventions. Materials and user guides are available at the IPOS website (see Appendix C). Training and orientation for staff members should include a detailed examination of the assessment questions, as well as the contextual use of the assessment to achieve DSRIP project 3.g.i and 3.g.ii goals.

Privacy

To identify patients, practices should use a unique member ID (such as medical record number), included on both the assessment and the data file format template (see Appendix B). PPS are expected to adhere to State and Federal laws as applicable to the handling of protected health information (PHI).

Reporting

The PPS will submit aggregated data from all participating practices or nursing homes to DOH through the Medicaid Analytics Performance Portal (MAPP). Aggregated data files will be submitted twice annually in accordance with the reporting schedule table below (see Table 1). PPS results will be calculated annually based on MY. Results should be formatted in a flat file according to the data file format template included in Appendix B.

Only each patient's most recent assessment at the time of filing will be used for measurement calculation. Regardless of the assessment used, staff must document whether an intervention was offered or provided corresponding to the needs of the patient. The "staff-only" section is designed to identify which patients were offered or provided an intervention based on the need identified by the patient response to the question.

Table 1: Reporting Schedule

DY	DY Dates	Payments Periods*	Measurement Year	File Submission Due
DY1	4/1/2015 to 3/31/2016	Payment 1: Q1 (5/01/2015)	MY1: N/A	N/A
		Payment 2: Q2 (1/01/2015)		
		Payment 3: Q4 (7/01/2016)		
DY2	4/1/2016 to 3/31/2017	Payment 1: Q2 (1/01/2017)	MY2: N/A	N/A
		Payment 2: Q4 (7/01/2017)		
DY3	4/1/2017 to 3/31/2018	Payment 1: Q2 (1/01/2018)	MY3: 1/1/2017 to 6/30/2017	N/A
		Payment 2: Q4 (7/01/2018)		DY3Q2 Report
DY4	4/1/2018 to 3/31/2019	Payment 1: Q2 (1/01/2019)	MY4: 7/1/2017 to 6/30/2018	DY4Q1 Report
		Payment 2: Q4 (7/01/2019)		DY4Q2 Report
DY5	4/1/2019 to 3/31/2020	Payment 1: Q2 (1/01/2020)	MY5: 7/1/2018 to 6/30/2019	DY4Q4 Report
		Payment 2: Q4 (7/01/2020)		DY5Q1 Report

*DSRIP Year 1 has 3 payment cycles. Payment 1 was based upon acceptance of PPS Applications. All other biannual payments are based upon pay for reporting or pay for performance.

Performance and Scoring Methodology

Projects 3.g.i and 3.g.ii are rewarded on a "pay for reporting" (P4R) methodology for DY2-3 and a "pay for performance" (P4P) methodology for DY4-5. During DY1 and DY2, PPS only need to satisfy Domain 1 reporting requirements to qualify for AVs. An initial PPS baseline is established during MY3 using data collected only during Q3 and Q4 of MY3. Subsequent AVs will be calculated against this baseline result using annual MY results.

There are four measures associated with the palliative care projects: physical symptoms, depression, peacefulness, and completion of advance directives; each measure aligns with a question in the IPOS assessment. Questions 2, 5, and 6 scored with a 2, 3, or 4 response or Question 10 scored with a 0 response identify a potential need for intervention:

- **Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick <u>one box</u> that best describes how it has <u>affected</u> you <u>over the past week</u>:**
- **Q5. Have you been feeling depressed?**[9]
- **Q6. Have you felt at peace?**[10]
- **Q10. Check all advance directives known to have been completed:**

The calculation for the pain measure is shown below:

<u>Numerator</u> Denominator	=	<u>Number of patients offered or provided an intervention for the question</u> Number of patients with responses 2, 3, or 4 for the question

The calculation for the physical symptom measure (i.e., includes shortness of breath, weakness or lack of energy, nausea, vomiting, poor appetite, constipation, sore or dry mouth, drowsiness, poor mobility) is shown below:

[9] Refers to the past week
[10] Refers to the past week

Numerator Denominator	=	Number of symptoms indicating that an intervention was offered or provided Number of symptoms with responses 2, 3, or 4 for the question

The calculation for the advanced directive measure is shown below:

Numerator Denominator	=	Number of patients offered or provided an intervention for the question Number of patients with response 4 (None)

In order for Performing Provider Systems (PPS) to earn Achievement Values (AVs), the PPS needs to have a ratio greater than 1 comparing most current measurement year (MY) result to baseline MY (see Forestland Example on page 8). In the event that MY3 results (baseline year) indicate a 100% performance level, subsequent P4P years (MY4 and MY5) will allow for a performance ratio of greater than or equal to 1.

Practices and nursing homes must create a reporting file to hold response data from each completed assessment throughout the measurement period according to the guidance included in Appendix B. Practices and nursing homes may choose to add additional information in the database, but must at a minimum capture these required fields.

PPS will be eligible for five potential AVs per year (one for each of the five measure questions). In order to earn AVs, the PPS must achieve a ratio of greater than one when compared to baseline year (MY3) performance levels. Although participating practices and nursing homes may administer assessments to all patients participating in palliative care including commercial, Medicare, and the uninsured, PPS results will only be calculated based on Medicaid patient assessments (see Appendix B: Insurance Type = 2, 5, 6, and 7) corresponding to those qualifying as actively engaged under the definitions provided above.

Audit Process

The assessments completed by individual practices or nursing homes should be securely submitted to the PPS every six months. The PPS is responsible for conducting an audit of the practices and nursing homes involved in this project to determine the accuracy of both the numerator and denominator (i.e., documentation in the medical record of identified need and intervention provided or offered). The PPS audit will be completed during the first year of implementation, with follow up as needed in subsequent years.

Audits should adhere to the following protocol:

1. The PPS randomly selects 10 percent of all completed assessments or 30 assessments (whichever is fewer) to be audited prior to submission of results. This audit must substantiate, through medical record reviews, that eligible patients were offered or provided an intervention where noted.
2. If this audit does not produce a replicable result in 25% or more of the audit cases, the PPS must audit all assessments included in its measurement year results using an external audit partner.
3. Should the full audit not yield a replicable result across 75% or greater of the assessments included in the measurement period, the PPS shall report this failed audit to the IA, triggering a full audit by the IA.
4. Based on the IA's audit, AVs may be reduced by a level corresponding to the variance between reported and audited findings.

Forestland Example

Table 2 outlines how the fictitious PPS, Forestland, scored across **one** performance measure (pain management) over the course of MY3-MY5.

- **MY3 (P4R):** Forestland submitted all reporting, therefore receives 1 AV. Baseline is established.
- **MY4 (P4P):** Forestland receives 1 AV, as a result of improving the performance ratio from the baseline year.
- **MY5 (P4P):** Forestland receives 0 AVs, as a result of **not** improving the performance ratio from the baseline year.

Table 2: Forestland Example

Measure	Performance	MY3	MY4	MY5
Pain Management	Number of patients offered or provided an intervention for the question	55	57	58
	Number of patients with responses 2, 3, or 4 for the question	70	66	76
	Performance Ratio	0.79	0.86	0.76
	Baseline Comparison	N/A	0.86 / 0.79 = **1.10**	0.76 / 0.79 = **0.97**
	AV Earned	**1**	**1**	**0**

The baseline result from MY3 (0.79 in this example) is used for comparison for all future years (MY4 and MY5 in this example).

Appendix A: Sample Assessments

Patient Version

IPOS Patient Version

www.pos-pal.org

STAFF COMPLETED
Practice Site Name: ..... Patient Identification #: .....
Assessment Date: ..... Setting: ❑ Office ❑ Nursing home
Assessment Type (check): ❑ Initial ❑ Status Change ❑ Routine
Insurance Type (check all that apply): ❑ Commercial ❑ Medicaid ❑ Medicare ❑ Uninsured

Q1. What have been your main problems or concerns over the past week?

1. _____
2. _____
3. _____

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick one box that best describes how it has affected you over the past week.

	Not at all	*Slightly*	*Moderately*	*Severely*	*Over-whelmingly*	STAFF COMPLETED *Intervention offered or provided?*
Pain	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes
Shortness of breath	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes
Weakness or lack of energy	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes
Nausea (feeling like you are going	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes
Vomiting (being sick)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes
Poor appetite	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes
Constipation	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes
Sore or dry mouth	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes
Drowsiness	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes
Poor mobility	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes

Please list any other symptoms not mentioned above, and tick one box to show how they have affected you over the past week.

1. _____	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes
2. _____	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes
3. _____	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes

IPOS PATIENT www.pos-pal.org Page 1 of 2 IPOSv1-P7-EN 26/02/2014

Over the past week:

	Not at all	Occasionally	Sometimes	Most of the time	Always	STAFF COMPLETED Intervention offered or provided?
Q3. Have you been feeling anxious or worried about your illness or treatment?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes
Q4. Have any of your family or friends been anxious or worried about you?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes
Q5. Have you been feeling depressed?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes

	Always	Most of the time	Sometimes	Occasionally	Not at all	STAFF COMPLETED Intervention offered or provided?
Q6. Have you felt at peace?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes
Q8. Have you had as much information as you wanted?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes

	Problems addressed/ No problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed	STAFF COMPLETED Intervention offered or provided?
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes

	Health Care Proxy	Living Will	Organ Donation	Documentation of Oral Advance Directive	None	STAFF COMPLETED Intervention offered or provided?
Q10 Check all advance directives known to have been completed:	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐ No ☐ Yes

	On my own	With help from a friend or relative	With help from a member of staff
Q11 How did you complete this questionnaire?	☐	☐	☐

If you are worried about any of the issues raised on this questionnaire then please speak to your doctor or nurse

Staff Version

IPOS Staff Version

www.pos-pal.org

Practice Site Name: ..... Patient Identification #: .....
Assessment Date: ..... Setting: ❑ Office ❑ Nursing home
Assessment Type (check): ❑ Initial ❑ Status Change ❑ Routine
Insurance Type (check all that apply): ❑ Commercial ❑ Medicaid ❑ Medicare ❑ Uninsured

Q1. What have been the patient's main problems over the past week?

1. _____
2. _____
3. _____

Q2. Please tick one box that best describes how the patient has been affected by each of the following symptoms over the past week

	Not at all	Slightly	Moderately	Severely	Over-whelmingly	Cannot assess (e.g. unconscious)	Intervention offered or provided?
Pain	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes
Shortness of breath	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes
Weakness or lackof energy	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes
Nausea (feeling like you are going to be sick)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes
Vomiting (being sick)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes
Poor appetite	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes
Constipation	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes
Sore or dry mouth	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes
Drowsiness	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes
Poor mobility	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes

Please list any other symptoms and tick one box to show how you feel each of these symptoms has affected the patient over the past week.

1. _____	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes
2. _____	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes
3. _____	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes

Over the past week:

	Not at all	Occasionally	Sometimes	Most of the time	Always	Cannot assess (e.g. unconscious)	Intervention offered or provided?
Q3. Has s/he been feeling anxious or worried about his/her illness or treatment?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes
Q4. Have any of his/her family or friends been anxious or worried about the patient?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes
Q5. Do you think s/he felt depressed?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes

	Always	Most of the time	Sometimes	Occasionally	Not at all	Cannot assess (e.g. unconscious)	Intervention offered or provided?
Q6. Do you think s/he has felt at peace?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes
Q7. Has the patient been able to share how s/he is feeling with his/her family or friends as much as s/he wanted?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes
Q8. Has the patient had as much information as s/he wanted?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes

	Problems addressed/ No problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed	Cannot assess (e.g. unconscious)	Intervention offered or provided?
Q9. Have any practical problems resulting from his/her illness been addressed? (such as financial or personal)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes

	Health Care Proxy	Living Will	Organ Donation	Documentation of Oral Advance Directive	None	Cannot assess (e.g. unconscious)	Intervention offered or provided?
Q10. Check all advance directives known to have been completed:	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ No ☐ Yes

IPOS-Dem

Practice Site Name: ..... Patient Identification #: .....
Assessment Date: ..... Setting: ❑ Office ❑ Nursing home
Assessment Type (check): ❑ Initial ❑ Status Change ❑ Routine
Insurance Type (check all that apply): ❑ Commercial ❑ Medicaid ❑ Medicare ❑ Uninsured

Q1. What have been the person's main problems over the past week?

1.....

2.....

3.....

Q2. Please select one box that best describes how the person has been affected by each of the following symptoms over the past week.

	Not at all	*Slightly*	*Moderately*	*Severely*	*Over-whelmingly*	*Cannot assess*	*Intervention offered or provided?*
Pain	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	❑ 0 No ❑ 1 Yes
Shortness of breath	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	❑ 0 No ❑ 1 Yes
Weakness or lack of energy	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	❑ 0 No ❑ 1 Yes
Nausea (feeling like being sick/vomiting)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	❑ 0 No ❑ 1 Yes
Vomiting (being sick)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	❑ 0 No ❑ 1 Yes
Poor appetite	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	❑ 0 No ❑ 1 Yes
Constipation	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	❑ 0 No ❑ 1 Yes
Dental problems or problems with dentures	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	❑ 0 No ❑ 1 Yes
Sore or dry mouth	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	❑ 0 No ❑ 1 Yes
Drowsiness (sleepiness)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	❑ 0 No ❑ 1 Yes
Poor mobility (trouble walking, cannot leave bed, falling)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	❑ 0 No ❑ 1 Yes

1

IPOS-Dem

	Not at all	*Slightly*	*Moderately*	*Severely*	*Over-whelmingly*	*Cannot assess*	*Intervention offered or provided?*
Swallowing problems (e.g. chokes, inhales food or drink, holds food in mouth)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes
Skin breakdown (redness, skin tearing, pressure damage)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes
Difficulty communicating	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes
Sleeping problems	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes
Diarrhoea	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes
Hallucinations (seeing or hearing things not present) and/or delusions (fixed false beliefs)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes
Agitation (restless, irritable, aggressive)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes
Wandering (as a result of distress or putting person at risk)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes

Has the person had any other symptoms? Please select one box to show how you feel each of these symptoms have affected the person over the past week (optional).

1.....0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes
2.....0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes
3.....0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes

IPOS-Dem

Over the past week:

	Not at all	Occasionally	Sometimes	Most of the time	Always	Cannot assess	Intervention offered or provided?
Q3. Has s/he been feeling anxious or worried?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes
Q4. Have any of his/her family been anxious or worried about the person?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes
Q5. Do you think s/he felt depressed?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes
Q5b. Lost interest in things s/he would normally enjoy?	☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes

Over the past week:

	Always	Most of the time	Sometimes	Occasionally	Not at all	Cannot assess	Intervention offered or provided?
Q6. Do you think s/he felt at peace?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes
Q7. Has s/he been able to interact positively with others (e.g. staff, family, residents)?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes
Q7b. Can s/he enjoy activities appropriate for his/her level of interests and abilities?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes
Q8. Has his/her family had as much information as wanted?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes

Over the past week:

	Problems addressed/ No problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed	Cannot assess	Intervention offered or provided?
Q9. Have all practical problems been addressed? [e.g. hearing aids, foot care, glasses, diet]	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes

	Health Care Proxy	Living Will	Organ Donation	Documentation of Oral Advance Directive	None	Cannot assess	Intervention offered or provided?
Q10. Check all advance directives known to have been completed:	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐	☐ 0 No ☐ 1 Yes

What was the person's last weight and the date s/he was last weighed? Weight .....lbs

3

Appendix B: Data File Format Template

- Data file must be in flat format. Fields should be left justified and blank filled for the column width. Each row should be 83 columns in length.
- All fields are required. For item 10, if there is more than one selection, use the additional fields to record all responses. If there is only one response, additional fields should be left blank.
- Each assessment should be a unique row in the file.

IPOS Assessment Data File Format Template

Column Placement	Variable Description	Value Labels	Details/Comments
1-2	PPS ID	2 Characters	Adirondack Health Institute = 23 Catholic Medical Partners = 46 CNY DSRIP Performing Provider System =08 Ellis Hospital = 03 Maimonides Medical Center = 33 Mohawk Valley PPS (Bassett) = 22 New York City Health and Hospitals-led PPS = 52 Richmond Univ Med Center & Staten Island Univ Hosp = 43 The New York Presbyterian Hospital = 39 The New York Hospital Medical Center of Queens = 40 United Health Services Hospitals, Inc = 44
3-32	Practice Site or Facility Name	30 Characters	
33-42	Unique Patient Identification #	10 Characters	Unique patient identification indicator (such as medical record number)
43-50	Assessment Date	8 Characters	mmddyyyy (do not include dashes or slashes), 99999999 if missing
51	Setting	1 Character	Office = 1, Nursing home = 2
52	Assessment Type	1 Character	Initial = 1 Change = 2 Routine = 3
53-54	Insurance Type	2 Character	Commercial only = 1 Medicaid only = 2 Medicare only = 3 Uninsured = 4 Medicaid and Medicare = 5 Medicaid and Commercial = 6 Medicaid, Medicare and Commercial = 7
55	Survey Version	1 Character	Patient = 1 Staff = 2 Other = 3 (for use in IPOS-Dem version)
56	Question # (pain) Score	1 Character	Score 0-4
57	Question # (pain) Intervention Indicator	1 Character	Yes = 1, No = 0
58	Question 2 (symptoms) Count	2 Characters	SUM OF all symptom related questions* (excluding pain symptom question) that have a score of 2, 3, or 4 Must report using leading zero for values less than ten

Column Placement	Variable Description	Value Labels	Details/Comments
			*IPOS Staff Survey includes symptom questions related to: shortness of breath, weakness or lack of energy, nausea, vomiting, poor appetite, constipation, sore or dry mouth, drowsiness, poor mobility. IPOS Patient Survey includes symptom questions related to: shortness of breath, weakness or lack of energy, nausea, vomiting, poor appetite, constipation, sore or dry mouth, drowsiness, poor mobility. IPOS Dem Survey (Non-Responsive Patients) includes symptom questions related to: shortness of breath, weakness or lack of energy, nausea, vomiting, poor appetite, constipation, dental problems, sore or dry mouth, drowsiness, poor mobility, swallowing problems, skin breakdown, difficulty communicating, sleeping problems, diarrhea, hallucinations, agitation, wandering.
59	Question 2 (symptoms) Intervention Count	2 Characters	SUM OF all symptom related questions* (excluding pain symptom question) that have a score of 2, 3, or 4 AND indicate “yes” for intervention offered/provided by staff Must report using leading zero for values less than ten *IPOS Staff Survey includes symptom questions related to: shortness of breath, weakness or lack of energy, nausea, vomiting, poor appetite, constipation, sore or dry mouth, drowsiness, poor mobility. IPOS Patient Survey includes symptom questions related to: shortness of breath, weakness or lack of energy, nausea, vomiting, poor appetite, constipation, sore or dry mouth, drowsiness, poor mobility. IPOS Dem Survey (Non-Responsive Patients) includes symptom questions related to: shortness of breath, weakness or lack of energy, nausea, vomiting, poor appetite, constipation, dental problems, sore or dry mouth, drowsiness, poor mobility, swallowing problems, skin breakdown, difficulty communicating, sleeping problems, diarrhea, hallucinations, agitation, wandering.
60	Question 3 (worried) Score	1 Character	Score 0-4
61	Question 3 (worried) Intervention Indicator	1 Character	Yes = 1, No = 0
62	Question 4 (anxious) Score	1 Character	Score 0-4
63	Question 4 (anxious) Intervention Indicator	1 Character	Yes = 1, No = 0
64	Question 5 (depressed) Score	1 Character	Score 0-4

Column Placement	Variable Description	Value Labels	Details/Comments
65	Question 5 (depressed) Intervention Indicator	1 Character	Yes = 1, No = 0
66	Question 6 Score (at peace)	1 Character	Score 0-4
67	Question 6 (at peace) Intervention Indicator	1 Character	Yes = 1, No = 0
68	Question 7 (share feelings) Score	1 Character	Score 0-4
69	Question 7 (share feelings) Intervention Indicator	1 Character	Yes = 1, No = 0
70	Question 8 (information)Score	1 Character	Score 0-4
71	Question 8 (information) Intervention Indicator	1 Character	Yes = 1, No = 0
72	Question 9 (practical problems) Score	1 Character	Score 0-4
73	Question 9 (practical problems) Intervention Indicator	1 Character	Yes = 1, No = 0
74	Question 10 (advance directives) Health Care Proxy	1 Character	Yes = 1, No = 0
75	Question 10 (advance directives) Living Will	1 Character	Yes = 1, No = 0
76	Question 10 (advance directives) Organ Donation	1 Character	Yes = 1, No = 0
77	Question 10 (advance directives) Documentation of Oral Advance Directive	1 Character	Yes = 1, No = 0
78	Question 10 (advance directives) None	1 Character	Yes = 1, No = 0
79	Question 10 (advance directives) Cannot assess	1 Character	Yes = 1, No = 0
80	Question 10 (advance directives) Intervention Indicator	1 Character	Yes = 1, No = 0
81	Question 11 (how questionnaire was completed) On my own	1 Character	Yes = 1, No = 0
82	Question 11 (how questionnaire was completed) With help from a friend or relative	1 Character	Yes = 1, No = 0
83	Question 11 (how questionnaire was completed) With help from a member of staff	1 Character	Yes = 1, No = 0

Appendix C: Integrated Palliative Care Outcome Scale Resources

To access relevant IPOS materials, register at the Palliative Care Outcome Scale website (pos-pal.org). Registration and all materials are free. From the “Downloads” tab, the “Resources” section offers many useful readings.

Implementation resources include:

- Center to Advance Palliative Care’s forum as a centralized source for educational resources, training materials and collaborative efforts
- DSRIP LinkedIn discussion forum

Additional resources include:

- HPCANYS
- Coalition for Compassionate Care of California
- Education in Palliative and End-of-Life Care
- Palliative Care Network of Wisconsin
- Respecting Choices
- Serious Illness Care Project/Ariadne Labs
- CSU Institute for Palliative Care
- End-of-Life Nursing Education Consortium of the American Association of Colleges of Nursing
- The Conversation Project
- PalliTalk
- VitalTalk